

# Autism Spectrum Disorders:

## Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment

A 2010 CONSENSUS PUBLICATION

### Missouri Autism Guidelines *Initiative*

*Sponsored by the Thompson Foundation for Autism and the Division of  
Developmental Disabilities, Missouri Department of Mental Health*



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Guidelines *Initiative*



# Missouri Autism Guidelines Initiative

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- The Missouri families who live with autism spectrum disorders (ASDs). It has been our goal to develop clear, consistent guidelines for earlier screening, accurate diagnosis, and thoughtful assessment for intervention planning, which directly result in earlier treatment and better outcomes. Our process was richer as a result of families' direct participation.
- The professionals who work daily with children with ASDs and their families. It is our hope that these *Guidelines*, built on the most recent research, will inform professionals' clinical judgment and assist them in making accurate diagnoses and recommendations on behalf of individuals and families.
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# Preface

Statistics on the prevalence and incidence of autism spectrum disorders (ASDs) are alarming. But it is the impact of ASDs on the lives of children and their families that was the catalyst for the Missouri Autism Guidelines Initiative, formed in 2008 by the Thompson Foundation for Autism and the Division of Developmental Disabilities, Missouri Department of Mental Health. The Thompson Foundation was established in 2007 to help support the breakthrough work of the Thompson Center for Autism in Columbia, MO, and other ASD-related initiatives. The Foundation's mission is to strengthen children and families affected by ASDs through raising awareness and support for interventions, education, and research. The Division of Developmental Disabilities provides services to Missouri citizens with developmental disabilities, including those diagnosed with ASDs. Established in 2008, the Office of Autism Services works within the Division of Developmental Disabilities to develop public policy and programs on behalf of Missourians with ASDs.

The Thompson Foundation and the Division of Developmental Disabilities were brought together by their shared belief that current research and scientific data would help inform clinical judgment for earlier, more accurate screening, diagnosis, and assessment for intervention planning. Knowing that outcomes are greatly improved with earlier diagnosis and treatment, the sponsors envisioned working from current evidence to determine best practices to facilitate these critical first steps. The result is this collaborative body of work, *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment*.

These *Guidelines* are a direct outcome of the State of Missouri's Blue Ribbon Panel on Autism. Convened by Missouri State Sen. Mike Gibbons in 2007 at the request of the Thompson Foundation for Autism, the Blue Ribbon Panel consisted of 16 members whose goal was to assist policymakers in recommending a better system to meet the needs of individuals with ASDs and their families. A number of the panel's recommendations alluded to the inconsistencies that characterize ASD practices in Missouri. In particular, Recommendation 17 focused directly on the need to establish best practices for screening, diagnosing, and assessing ASDs:

*The Blue Ribbon Panel recommends that there be established a committee of major stakeholders to adopt screening, diagnosis, assessment, and treatment standards for Missouri. The Missouri Commission on Autism Spectrum Disorders and Office of Autism Services should be utilized to recommend participants in this group.*

The report also cited the California Department of Developmental Services' published best practices, *Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment*, which addressed the need in California for improved and consistent protocols on behalf of children and adolescents with ASDs.

In response to the recommendation from Missouri's Blue Ribbon Panel and backed with permission to use California's document as the basis for a Missouri-specific project, the Thompson Foundation and the Division of Developmental Disabilities established the Missouri Autism Guidelines Initiative and convened a project leadership team in the fall of 2008. The group began by seeking nominations for the panel of parents and professionals who would formulate the *Guidelines*. The team agreed that this panel should consist of experts from across Missouri including physicians and psychologists; professionals who inform the diagnostic and assessment for intervention planning processes; educators,



including higher education; parents of children with ASDs, representing the lifespan; and representatives of the Division of Developmental Disabilities.

In December 2008, Missouri's newly formed Commission on Autism Spectrum Disorders endorsed the formation of the Missouri Autism Guidelines Initiative. Members of the Commission were also invited to nominate potential members to serve on the panel. All members selected for the Initiative agreed to collaborate to set the policies underlying the *Guidelines*; to review those policies through the newest science in ASD screening, diagnosis, and assessment for intervention planning; to inform their stakeholder groups of the process driving the *Guidelines*; and to assist in embedding the *Guidelines* in the organizations that they represent.

The panel worked throughout 2009, employing a consensus process reinforced by members' understanding of Missouri practice, culture, and resources. A key step in this process was a literature review, prepared by staff and accessed through the project's proprietary web site, that gave participants access to the latest ASD research and data. The result is a set of clear, concise *Guidelines* supported by an innovative conceptual framework that is unique among ASD practices nationwide.

Throughout the research, development, writing, and review of these *Guidelines*, the members of the Missouri Autism Guidelines Initiative focused on a set of clearly defined project goals:

- to enable and enhance communication among professionals involved in ASD screening, diagnosis, and assessment for intervention planning;
- to improve and expand the referral network for health care professionals;
- to serve as a foundation for training parents, health care professionals, educators, and others involved in the screening, diagnosis, and assessment processes;
- and, most important, to be the stimulus for earlier diagnosis leading to earlier and more effective treatment of those affected by ASDs.

Although the causes of ASDs are not fully understood, the ASD prevalence rate is increasing. The development and publication of these *Guidelines* increase the likelihood that every child in Missouri, regardless of age, income, ethnicity, or region, is screened, diagnosed, and assessed for intervention planning. The real impact for families will come now, as all those who have the opportunity and responsibility to intervene on behalf of Missouri's children put these practices into effect.

# Overview

## CHAPTER 1



# Introduction

These *Guidelines* provide recommendations, guidance, and information about current best practice in screening, diagnostic, and assessment services for individuals with autism spectrum disorders (ASDs). Tailored for Missouri health and education professionals and families of individuals with ASDs, the *Guidelines* are intended to help with informed decision making regarding identification, diagnosis, and assessment for intervention planning. These *Guidelines* represent general consensus among members of the Missouri Autism Guidelines Initiative regarding the publication's content and intended use. Although its content is informed by current literature and research, the document is not intended to provide an extensive review of related research.

The information is organized into three major chapters: screening, diagnostic evaluation, and assessment for intervention planning. Each chapter is written to stand alone to facilitate understanding and implementation by various groups. For that reason there is some repetition of key concepts from chapter to chapter. Each chapter includes a variety of tools to assist the reader to better understand the text and its applicability to practice. For example, Best Practice Recommendations are distilled from the text and printed in side bars. They are also summarized in Appendix A. In addition, case examples have been developed to further expand on key points within the text.

## Autism Spectrum Disorders (ASDs)

### ASDs DEFINED

Autism spectrum disorders (ASDs) are a group of neurodevelopmental disorders characterized by impaired social interaction and communication and by restricted or repetitive behaviors. These features are generally identified by the age of 3 years and are frequently associated with other physical and mental health conditions. The developmental challenges and associated problems in individuals with ASDs vary widely. Symptom presentation and degree of impairment can vary not only among individuals but also within the same individual over time.

The *Diagnostic and Statistical Manual, 4<sup>th</sup> edition, Text Revision (DSM-IV-TR)* published by the American Psychiatric Association (2000) is the current standard for the diagnosis and classification of ASDs by health or mental health professionals. The conditions on the autism spectrum addressed in these *Guidelines* include the *DSM-IV-TR* categories of Pervasive Developmental Disorders: Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger's Disorder. Use of the *DSM-IV-TR* for formal diagnostic classification requires specialized clinical training. A revision of the *DSM-IV-TR* is anticipated in 2012, and several issues are expected to be addressed in the new *DSM-V* that includes revision of specific ASD constructs that may impact ASD diagnosis. These *Guidelines* address issues related to screening, diagnosis, and assessment for intervention planning in a comprehensive and flexible manner that are likely to be adaptable to any changes in *DSM* constructs or criteria.

## IMPACT OF ASDs ON FAMILIES

Scientific research has documented several ways in which families are impacted by having a child with an ASD. Parents of children with ASDs experience greater stress, depression, anxiety, and other negative health outcomes than parents of children with other disabilities (Waisman Center, 2008). Further, caring for a child with an ASD is complicated and often requires access to many support services, including primary and specialty health care, early intervention and special education services, services provided by mental health providers, and other community resources such as specially trained child care and respite providers. Families often report significant gaps in care, difficulties navigating the complex care system, and financial strain that add to the challenges of raising a child with an ASD (Missouri Blue Ribbon Panel, 2008). Current estimates indicate that ASD-related costs to society range from \$35 to \$90 billion annually (Ganz, 2007).

# Definitions of Other Key Terms

## ASD SCREENING

ASD screening refers to the use of specific standardized instruments to identify an individual's risk for an ASD.

## ASSESSMENT FOR INTERVENTION PLANNING

Assessment for intervention planning is a term that describes the process of determining each individual's specific strengths and concerns to inform the intervention planning process.

## BEST PRACTICE RECOMMENDATIONS

These *Guidelines* offer recommendations for best practice that are not intended to be interpreted as policy or regulation but as tools designed to help healthcare providers, educators, and families make informed decisions regarding screening, diagnosis, and assessment for intervention planning.

## DEVELOPMENTAL SCREENING

Screening refers to the use of standardized instruments to identify and refine an individual's risk for developmental delays.

## DEVELOPMENTAL SURVEILLANCE

Developmental surveillance is the routine monitoring and tracking of specific developmental milestones, typically by physicians and primary care providers (PCPs) at well-child visits. This process of recognizing children who may be at risk for developmental delays is also conducted by other community professionals such as teachers and child care workers who routinely come into contact with young children.

## DIAGNOSTIC EVALUATION

The terms “diagnostic evaluation” and “evaluation” refer to the diagnostic process aimed at identifying specific developmental disorders that are affecting a person suspected of having an ASD and the rendering of a *DSM-IV-TR* diagnosis by a physician, psychologist, or other health or mental health professional.

## EVALUATION TO DETERMINE ELIGIBILITY FOR SPECIAL EDUCATION AND RELATED SERVICES

In public schools, evaluation under the Individuals with Disabilities Education Improvement Act of 2004 (IDEA) refers to an evaluation process conducted by a multidisciplinary team, including parents, for the purpose of determining a child's eligibility to receive special education and related services.

## LEAD DIAGNOSTIC CLINICIAN

The term lead diagnostic clinician refers to the licensed physician, psychologist, or health or mental health professional with knowledge and experience related to ASDs who performs evaluations for ASD diagnoses. The lead diagnostic clinician may be the same professional who provides ongoing care or may be a consulting specialist.

## PRIMARY CARE PROVIDERS (PCPs)

The term primary care providers refers to physicians (e.g., pediatricians, family physicians) and other healthcare professionals (e.g., nurse practitioners) licensed to provide a broad spectrum of preventive and general health care.

## SERVICE COORDINATOR

In Missouri, many state departments, county developmental disability boards, and community mental health centers assign a service coordinator or case manager to an individual or family. The coordinator is responsible for developing the individual support or service plan and assists in finding service providers.

# Guiding Principles for Missouri's ASD Services

Several principles guided the development of this document: (a) family-centered care, (b) early identification, (c) informed clinical judgment, and (d) community collaboration. Each will be described below.

## FAMILY-CENTERED CARE

Throughout these *Guidelines*, a family-centered frame of reference reinforces the concept of parents and caregivers as the most knowledgeable source of information about the child, acknowledges that the child and family are part of a larger community system, and sets the stage for ongoing collaboration and communication between professionals and family members. The needs, priorities, and resources of the family are understood to be the primary focus and are respectfully considered during each step of the process: screening, diagnostic evaluation, and assessment for intervention planning.

A family-centered frame of reference includes cultural sensitivity and regard for family and community diversity of cultural values, language, religion, education, socio-economic, and social-emotional factors that influence the family's ability to cope with the challenges of an ASD. Families are treated as equal partners in the diagnostic evaluation and assessment for intervention planning processes in order to enhance their capacity to meet the needs of the individual with an ASD.

## EARLY IDENTIFICATION

Early identification of young children with ASDs can lead to earlier entry into intervention programs that support improved developmental outcomes (Johnson, Myers, & the Council on Children with Disabilities, 2007; Sallows & Graupner, 2005; Wiggins, Baio, & Rice, 2006). Early intervention has been associated with gains in verbal and nonverbal communication, higher intelligence test scores, and improved peer interactions (Wiggins et al., 2006). A substantial benefit of early intervention is the positive impact on the family's ability to interact in a manner that facilitates their child's development and to have a greater understanding of their child's disability and how it interacts with family life (Committee on Children with Disabilities, 1994). Early identification and diagnosis (a) enhances the opportunity for effective educational and behavioral intervention, (b) results in reduction of family stress by giving the family specific techniques and guidance for decision making, and (c) improves access to medical care and other types of support (Cox et al., 1999). Early intervention can improve both developmental functioning and the quality of life for the individual and his or her family (Eikeseth, Smith, Jahr, & Eldevik, 2007; Howlin, 2008; Rogers & Vismara, 2008).

Best practice recommends that screening and diagnosis occur as early in a child's life as possible. The characteristics of an ASD usually appear before the age of 3 years, and ASDs can sometimes be diagnosed as early as 18 months (Charman et al., 2005; Eaves & Ho, 2004; Lord, 1995; Pinto-Martin, Souders, Giarelli, & Levy, 2005; Wimpory, Hobson, Williams, & Nash, 2000). However, the average age of diagnosis across the nation continues to be well past 3 years (Centers for Disease Control [CDC], 2007; Shattuck et al., 2009; Wiggins et al., 2006) often long after parents first express concern to physicians (Chawarska, Klin, Paul, & Volkmar, 2007; Interactive Autism Network [IAN] StateStats, 2009).

There also may be racial disparities in the diagnosis of ASDs (Liptak et al., 2008; Mandell & Palmer, 2009). In a study of children in the St. Louis metropolitan area who were 8 years old in 2002, Black children meeting criteria for an ASD were less likely than White children to have an autism diagnosis in their health records. Furthermore, the median age of autism diagnosis among Black children was 8.2 years old, whereas the median age of diagnosis for White children was 5.5 years old (Shattuck, Constantino, & Fitzgerald, 2008).

To improve detection rates, the American Academy of Pediatrics recommends general developmental screening tests be administered regularly at 9-, 18-, and 30-month well-child visits and has initiated national efforts to improve developmental screening in the primary care setting. Specific routine screening for ASDs is recommended at 18 and 24 months (Myers et al., 2007).

## INFORMED CLINICAL JUDGMENT

Currently, there are no biomedical markers or laboratory tests for identifying children who meet the diagnostic criteria for an ASD. Accurate identification is entirely dependent on obtaining a complete developmental history and on direct interaction and behavioral observations. The importance of informed clinical judgment by health or mental health professionals responsible for diagnostic evaluation of an ASD cannot be overemphasized (Bagnato, McKeating-Esterle, Fevola, Bortolamasi, & Neisworth, 2008).

Although identification of an ASD is usually made during childhood, it is important to recognize that an ASD is typically a lifelong disability that affects the individual's adaptive functioning from childhood through adulthood to varying extents. To diagnose an ASD, the clinician must be familiar with typical and atypical child development, including age-appropriate behaviors, and have training and clinical experience with the ASD population.



Because ASDs have been found across a range of cognitive abilities, differential diagnosis requires familiarity with the presentation of ASDs in individuals with impaired, average, and advanced cognitive abilities. Furthermore, clinicians must be skilled at distinguishing ASDs from other types of childhood psychiatric and developmental disorders.

Clinicians who make an ASD diagnosis shall have at a minimum:

- Missouri state licensure as a physician, psychologist, or other health or mental health professional; and
- advanced training and clinical experience in the diagnosis and treatment of ASDs and related neurodevelopmental disorders, including knowledge about typical and atypical child development and experience with the variability within the ASD population.

Rapid developments in conceptualization, measurement, and basic research on ASDs require a commitment to periodic review of new discoveries and current best practices. This necessitates ongoing education and training opportunities for diagnostic clinicians. The clinical challenge is to stay current with new methods of evaluation and treatment, learn about and obtain the latest screening and diagnostic instruments, and maintain an awareness of local and regional community resources that meet the child's and family's needs. Using these resources adds to the clinician's diagnostic accuracy and allows for a better understanding of the individual, leading to better treatment and care.

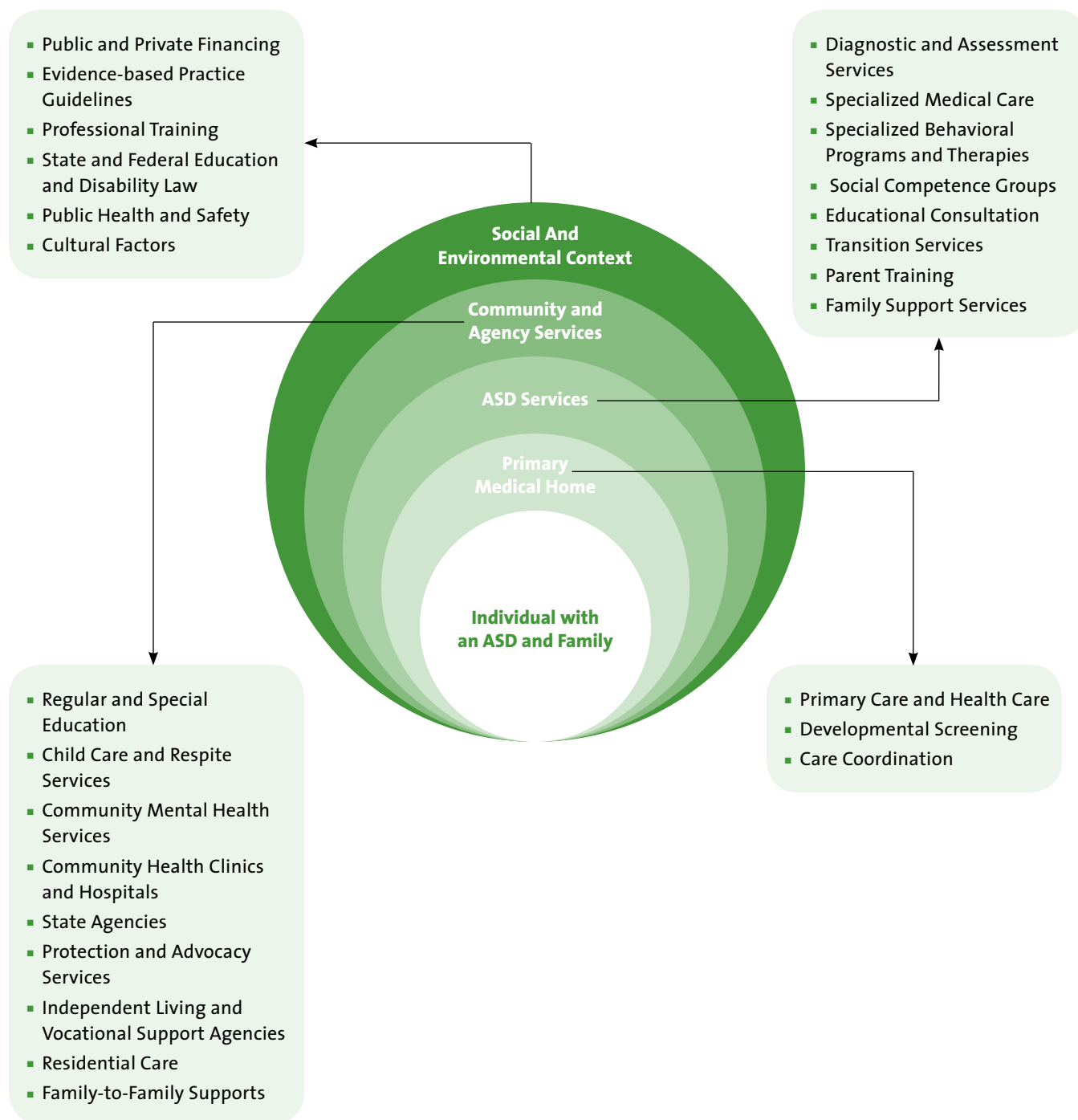
### COMMUNITY COLLABORATION

Autism spectrum disorders affect multiple developmental domains. The complexity of these disorders necessitates a range of services that are tailored to the needs of families, from screening and referral services through diagnosis, assessment for intervention planning, and treatment. A comprehensive approach typically requires the involvement of a team of professionals from a number of disciplines (e.g., primary and specialty physicians, nurses, psychologists, speech-language professionals, audiologists, occupational therapists, social workers, behavioral and educational specialists, teachers). Consistent with national recommendations for ASD service delivery (Interagency Autism Coordinating Committee, 2005), these *Guidelines* promote interdisciplinary and interagency collaboration among the referred individual, the family, and the service delivery systems.

Missouri's approach to providing these comprehensive services acknowledges that an individual with an ASD and his or her family have available a wide range of services. In addition to ASD or disability-specific care, this framework acknowledges the individual's need to access community and agency services while also taking into account current social and environmental factors such as state laws, availability of public and private health insurance, and cultural factors (see Figure 1.1).

## COMMUNITY COLLABORATION MODEL

FIGURE 1.1



The concept of community collaboration is integrated throughout this publication as a way to promote discussion among clinicians, educators, state programs, researchers, and families as they move toward improved community-based services for persons with ASDs. Given that this model encourages interagency collaboration, it is recognized that the exchange of information among clinicians and agencies places ethical and legal responsibilities on those professionals to obtain informed consent and share only information that is clinically pertinent. Professionals are encouraged to discuss with families the many potential benefits of shared information across systems of care, including improved coordination of care among agency staff and professionals who can improve outcomes for the individual with an ASD.

In addition to developing processes to share pertinent information appropriately, professionals are encouraged to become informed about the similarities and differences among the various systems of care—organizations, agencies, and other entities—each of which has its own mission and related policies and procedures. Clinicians can then share this information and understanding with families.

## Access to ASD Services in Missouri

Missouri's expanding networks of well-trained and experienced ASD clinicians are encouraged to work collaboratively to identify individuals at risk for ASDs and ensure accurate diagnostic evaluation and assessment for intervention planning. The intent of this collaborative approach is to improve outcomes for individuals with ASDs by promoting the early identification and timely entry into a full range of appropriate community-based services. This process consists of *three steps*: screening, diagnostic evaluation, and assessment for intervention planning. To assist the reader to better understand the publication's text regarding these processes, the authors have developed flow charts that describe each of the steps. Although the charts appear linear, the processes often are not, neither are they the same for all families.

### SCREENING FOR AUTISM SPECTRUM DISORDERS

#### Screening for ASDs in Children Birth to Age Five

Early diagnosis depends on listening carefully to parents' concerns about their child's development and behavior. Current research suggests that the concerns of parents whose children were later diagnosed with developmental problems are generally accurate (Glascoe, 2001). Whether these concerns are heard by a pediatrician, family physician, nurse practitioner, child care provider, teacher, or other health or education provider, families are encouraged to make arrangements for children suspected of having developmental delays to be screened by a trained professional using standardized screening instruments and clinical judgment. Screening instruments are not intended to provide diagnoses but rather to determine whether there is a need for further diagnostic evaluation.

The American Academy of Pediatrics Council on Children with Disabilities recommends that pediatricians and other PCPs conduct developmental surveillance and screening as a part of routine well-child care (Myers et al., 2007). There are screening instruments that can be completed by parents and scored by non-physician personnel in a healthcare provider's office. All screening instruments have limitations, but the PCP should choose and become familiar with an ASD screening instrument for each age group and use it consistently. This document includes resources that can guide screening efforts. Table 2.2 in Chapter Two lists ASD Screening Instruments and provides information about how to access them. Appendix D-2 includes a copy of the *Modified Checklist for Autism in Toddlers (M-CHAT)*, validated for screening toddlers between 16 and 30 months of age to assess risk for ASDs. In addition, Appendix D-1 includes a list of screening instruments recommended for

assessing general development. These instruments allow systematic detection of general developmental delays (e.g., delays in communication and cognitive functioning) that may be associated with ASDs in young children, but they are not designed to detect a specific ASD.

The PCP reviews the screening results with the family to support their efforts to understand their child's behaviors and encourages prompt action for further evaluation. PCPs also make the referral for a diagnostic evaluation, if indicated. When PCPs are unable to provide screening services, referrals for screening can be made to other trained providers in the community. Appendix E includes a list of resources for parents and professionals related to screening and, when appropriate, referral for diagnostic evaluation. Some of the materials and websites included on this list may be helpful to parents and professionals as initial discussions about ASDs unfold.

### Screening for ASDs in Children Age Six and Older

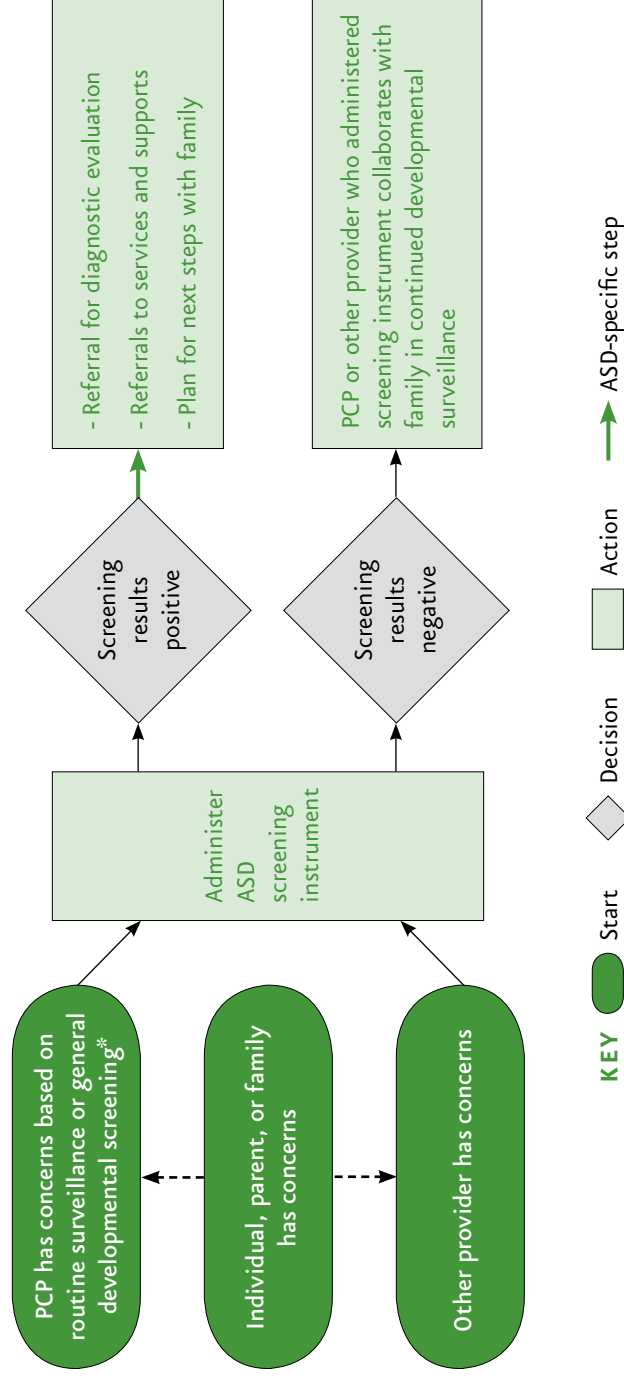
Although the core impairments in individuals with ASDs are commonly identified in early childhood, a considerable number of children are not recognized as being at risk for ASDs until school age or later. In these cases, families, educators and/or young adults themselves may have concerns regarding social and communication impairments and atypical behaviors. Screening instruments designed for young children are not particularly useful in this age group. However, several screening instruments are available for use with older children and adolescents up to age 18. Professionals may consider additional sources of information across environments prior to referral, including behavioral observations, history provided by parents, and/or records about the child's developmental trajectory. Ultimately, if the professional or parent still has questions about ASDs, referral for further evaluation is warranted.

### Referral for Diagnostic Services

When concerns arise that an individual may have an ASD, the family is consulted and a referral is made to a physician, psychologist, or other health or mental health professional who is licensed and qualified to make a diagnosis. Best practice suggests scheduling referrals as quickly as possible. The importance of expedited referrals cannot be overemphasized because recent research indicates that children with ASDs are not diagnosed, on average, until 13 months after initial screening by a qualified professional (Wiggins et al., 2006). Figure 1.2 summarizes the steps in the screening process that lead to referral for diagnostic evaluation and appropriate services and supports for the individual and his or her family when the screening result is positive.

## THE PROCESS TO SCREEN FOR AUTISM SPECTRUM DISORDERS

FIGURE 1.2



\* Routine screening by Primary Care Provider (PCP) is recommended at 18 and 24 months

## MISSOURI'S TIERED APPROACH TO DIAGNOSTIC EVALUATION

Diagnostic evaluation answers the question, “Is an ASD diagnosis warranted?” The purpose of the diagnostic evaluation is to collect sufficient data in the social, communication, and behavioral domains required by diagnostic criteria to determine whether an individual fits into a particular diagnostic category. In this document, the professional responsible for conducting the evaluation is referred to as the lead diagnostic clinician. This clinician must have the capacity to conduct an evaluation that includes two essential components: the individual’s history *and* direct interaction with and behavioral observation of the individual.

In Missouri, a tiered approach to the diagnosis of ASD is recommended in order to provide access to diagnostic evaluation as early as possible without compromising diagnostic accuracy. The tiered approach is based on the recognition that the need for standardized measures and consultation with other professionals varies based on the presentation of the individual being evaluated and the clinical competencies of the lead clinician.

Diagnostic accuracy is impacted by four key elements: the lead diagnostic clinician’s experience and judgment, the use of standardized instruments, consultation with other professionals, and the complexity of presentation of symptoms. These key elements are described below.

### Lead Diagnostic Clinician’s Experience and Judgment

As noted, in Missouri the lead diagnostic clinician is a physician, psychologist, or other health or mental health professional who is licensed and qualified to render a diagnosis of ASD. This clinician may be practicing independently or as part of a larger multidisciplinary team and is responsible for collecting and reviewing adequate information so that the ASD diagnosis is based on current *DSM-IV-TR* criteria.

### Use of Standardized Instruments

Specific standardized instruments are available that aid the clinician in gathering relevant information and evaluating specific ASD impairments (see Appendix F). Research has demonstrated that the use of these instruments adds incremental value to diagnostic accuracy (Lord et al., 2006).

### Consultation with Other Professionals

As indicated, a single clinician's judgment can be enriched by including the perspectives of other specialists who interact with or have assessed the individual.

### Complexity of Presentation of Symptoms by Individuals with ASDs

The severity of symptom presentation and the age of the individual can have an impact on the complexity of the diagnostic process and the accuracy of the diagnosis.

### Levels of Diagnostic Evaluation

The approach in these *Guidelines* encourages the lead diagnostic clinician to determine the level of evaluation required for a diagnosis, with each advancing level incorporating increasingly sophisticated diagnostic methods, instruments, and consultation with other professionals. The lead diagnostic clinician selects the level of evaluation that best fits the needs of the individual being evaluated. For clarity, these *Guidelines* define the three levels of diagnostic evaluation as Tier 1, Tier 2, and Tier 3. ( See Table 1.1.)

**TIER 1:** The lead diagnostic clinician determines that he or she is able to *independently* make a diagnosis or rule out an ASD based on clinical judgment. The clinician may or may not choose to use standardized instruments to inform clinical judgment.

Tier 1 recognizes that there are individuals whose ASD symptoms are severe enough and/or whose diagnosis is clear enough to an experienced clinician that a diagnosis can be rendered without the immediate need for consultation with other specialists or use of standardized instruments.

**TIER 2:** When an individual has a more complex presentation, the lead clinician uses data from standardized diagnostic instruments and may also consider consultation with at least one other professional, as indicated, to inform his or her clinical judgment about whether an ASD diagnosis is warranted.

**TIER 3:** Individuals with very complex presentations (presentation with some ASD symptoms and multiple coexisting concerns, or complex medical or psychosocial history) may require an even broader and more sophisticated approach to inform clinical judgment about whether an ASD diagnosis is warranted. In these cases, the lead diagnostic clinician may work with a team of professionals who have specific areas of expertise such as speech-language, occupational therapy, medical specialties, or psychology. In these cases, use of a multi-disciplinary team often improves diagnostic certainty by drawing on diverse specialty knowledge and training.



Clinicians should remain sensitive to parents’ concerns regarding the completeness of the evaluation. For example, if the clinician conducts a Tier 1 evaluation and comes to a diagnostic conclusion but the parents remain concerned and request a more comprehensive evaluation (e.g., the parents feel that the evaluation was not representative of the child’s typical functioning), the clinician involves other professionals for a higher tier diagnostic evaluation or refers the family to others for further diagnostic testing.

OVERVIEW OF DIAGNOSTIC EVALUATION TIERS				TABLE 1.1
	INDIVIDUAL PRESENTATION	USE OF STANDARDIZED INSTRUMENTS	CONSULTATION WITH OTHER PROFESSIONALS	
TIER 1	Presentation of symptoms that unambiguously indicate an ASD	May be used; not required	None	
TIER 2	Milder or more complex symptoms, difficult differential diagnosis, question about cognitive level	Yes	Possibly; consult with at least one other professional, as indicated	
TIER 3	Very subtle or complex symptoms, some ASD symptoms with multiple co-existing concerns, complex medical or psychosocial history	Yes	Yes; consult with multiple other professionals	

Several standardized instruments are available to assist with the diagnostic evaluation, as appropriate. A listing of diagnostic instruments is included as Appendix F.

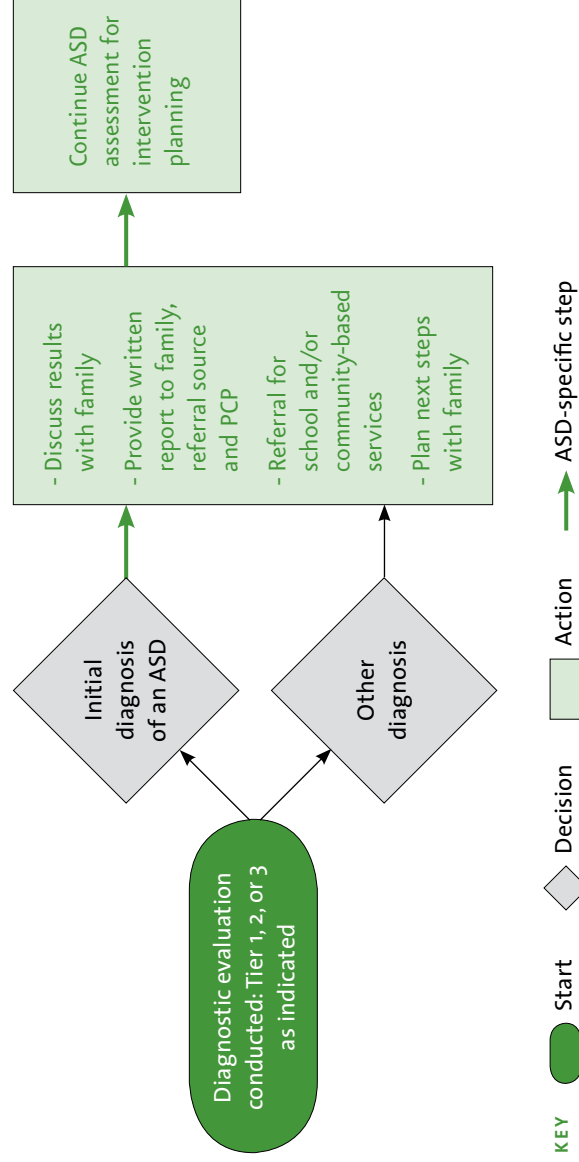
After conducting a diagnostic evaluation, the lead diagnostic clinician discusses with the family the outcomes of the evaluation, possible referral to other health professionals for further assessment to prepare for the selection of the appropriate intervention, and the family’s preferences for follow-up care.

Importantly, throughout this process, the lead diagnostic clinician distinguishes between the *medical diagnosis* and *educational eligibility*. The medical diagnostic process seeks a diagnostic determination that leads to treatment recommendations, whereas educational evaluations are designed to determine whether the child meets the state’s educational eligibility criteria for special educational services. The challenge often is to achieve the optimal level of collaboration and communication among the family and various professionals and agencies involved in the medical diagnosis and educational eligibility processes.

The diagnostic evaluation is designed to address issues that include parents’ concerns, priorities, and resources. Parents often have questions regarding the meaning of the diagnosis for their child and family and the intervention approaches that can help them address the needs of *their particular child*. Best practice recommends that the lead diagnostic clinician build a partnership with parents and caregivers throughout the diagnostic evaluation process. This partnership recognizes and respects parents’ expertise about their child and focuses on parent questions and concerns. The process of diagnostic evaluation is summarized in Figure 1.3.

## THE PROCESS OF DIAGNOSTIC EVALUATION

FIGURE 1.3



## ASSESSMENT FOR INTERVENTION PLANNING

Assessment is a continuous and ongoing process. It answers the question, “What individual strengths and concerns should guide intervention planning?” Although it is possible for an independent professional or professionals representing one or two areas of expertise to make an ASD diagnosis, assessment for intervention planning requires involvement of professionals representing multiple disciplines. Often these professionals are part of a network of services that includes medical, educational, and other community-based services, each with its own assessment process. Families work collaboratively with professionals from each of these service systems to integrate the various assessment findings into a comprehensive profile of the individual’s strengths and concerns. This profile becomes the family’s basis for planning for the selection of specific interventions.

These *Guidelines* focus primarily on *clinical/medical* assessment for intervention planning. In this context, assessment goes beyond the categorical diagnosis to examine the individual’s functioning across *multiple* domains with the express objective of directing treatment planning and intervention based on the child’s and family’s individual profile. The lead clinician collaborates with the family to determine the need for and priority of assessment related to each of the following essential components:

- cognitive and academic functioning;
- adaptive functioning;
- social, emotional, and behavioral functioning;
- communication;
- comprehensive medical examination;
- sensory and motor functioning; and
- family functioning.

Assessment in each component is based on family concerns, clinical indicators, the individual’s intervention history, and data available from prior assessments. Additional clinical assessment that is needed for intervention planning depends on the nature of the diagnostic evaluation, such as the areas of expertise of the professionals involved in the diagnostic process, the number of domains assessed, and the depth of the assessment

in each domain. In Missouri's tiered approach to diagnostic evaluation, the extent of additional clinical assessment needed for intervention planning is directly related to whether the diagnostic evaluation was completed at Tier 1, Tier 2, or Tier 3.

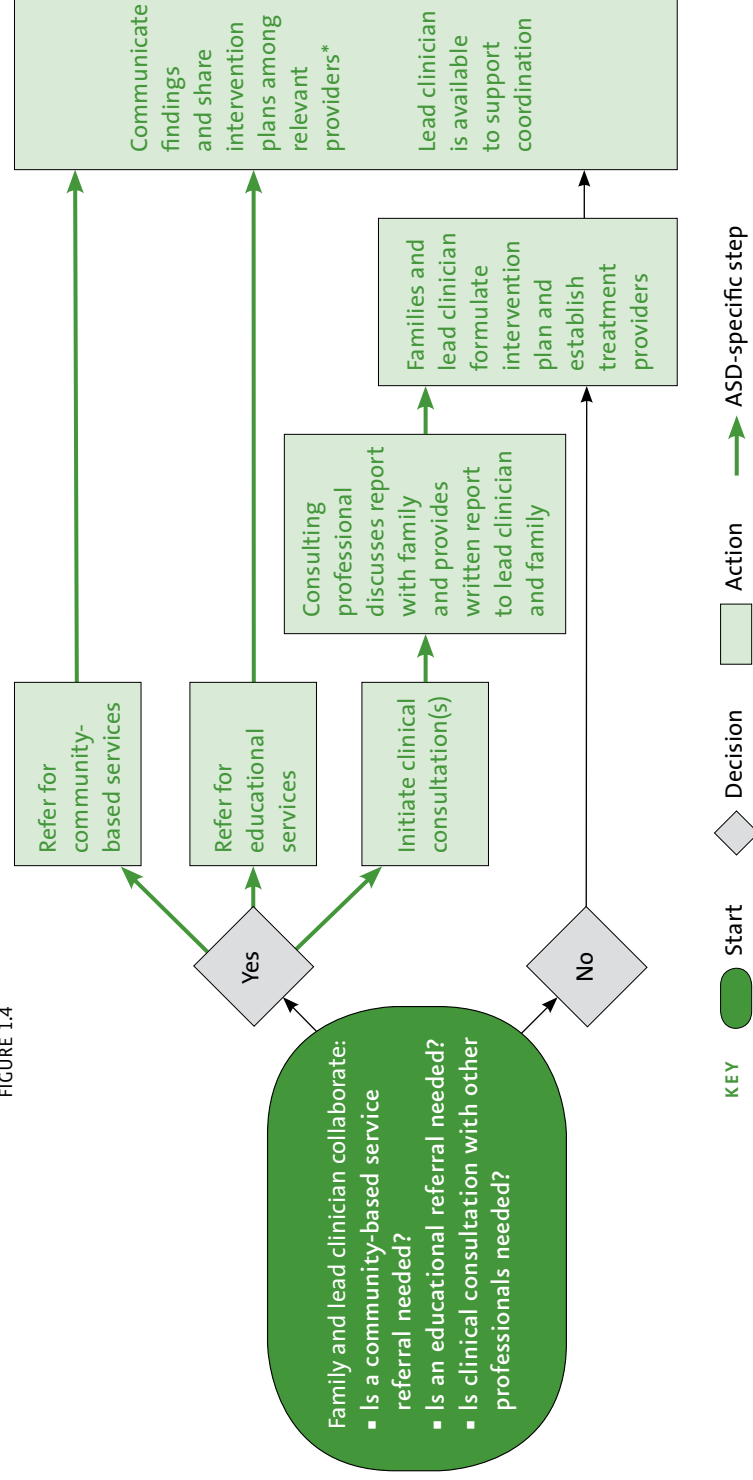
For each of the essential components listed previously, there are several instruments that can assist in the assessment process. Because of the complexity and quantity of information related to these instruments and their use in the assessment process, Chapter Four has been divided into two sections. Section One provides an overview of the process of clinical assessment for intervention planning. Section Two provides an in-depth discussion of the technical aspects of assessment of each of the essential components. In addition, Appendix G provides an extensive list of instruments for each of the essential components.

Diagnostic evaluation and assessment for intervention planning may or may not occur at the same time. However, multidisciplinary evaluations have the advantage of providing both diagnostic and assessment services at the same time and place, which may be an advantage for some families.

Assessment involves professionals representing multiple disciplines who have expertise in their own fields and specific training and experience with ASDs. Professionals are encouraged to discuss openly their credentials and experience with ASDs with individuals involved in the assessment process including parents or other family members. The lead clinician collaborates with the family to integrate the findings of the various professionals who contribute to the assessment process to create an individual profile that is detailed, concrete, and easily understood by the child's family and other care providers, and that provides a basis for individualized recommendations regarding interventions. The assessment process is summarized in Figure 1.4.

## THE ASSESSMENT FOR INTERVENTION PLANNING PROCESS

FIGURE 1.4



\* Findings are reported in a manner that facilitates usability across settings

Although these *Guidelines* focus primarily on clinical assessment, schools and other community-based services often provide vital information that may be of assistance to comprehensive planning for intervention. Gaps in communication among these three service systems often are identified as a cause of confusion and frustration for individuals with ASD and their families. Therefore, it is essential for clinicians to understand the similarities and distinctions among these three systems. A brief discussion of the three systems follows. In addition, Table 1.2 compares assessments by clinical/medical, educational, and other service systems.

### Clinical/Medical Assessment for Intervention Planning

Clinical/medical assessment (or clinical assessment) for intervention planning derives from diagnostic evaluation in which established medical diagnostic criteria (*DSM-IV-TR*) are used to make a medical diagnosis of an ASD. Clinical assessment for intervention planning addresses ASDs as neurobiological disorders that may manifest in multiple areas of neurodevelopment and require intervention across medical, educational, home, and community settings. Consideration of information from educators and community service providers enhances clinical assessment. Assessment results in a treatment plan that includes recommendations and referrals related to behavioral interventions; outpatient services such as specific medical treatment, medication management, speech and language therapy, occupational therapy, physical therapy, psychological intervention, or family therapy; educational strategies; and community-based resources and support services, especially those that may require a medical diagnosis or clinical documentation for eligibility. Clinicians also may inform families about opportunities for research participation.

An individual with a medical diagnosis of an ASD may or may not be eligible for special education services or other programs designed for individuals with disabilities.

### Educational Evaluation and Assessment

Educational evaluation and assessment is a mandatory process under the Individuals with Disabilities Education Improvement Act of 2004 (IDEA)—the legal and regulatory basis for special education in public schools. The *Missouri State Plan for Special Education* (DESE, 2007) details how public schools in Missouri will comply with the federal law when evaluating and educating children with disabilities. The First Steps program for young children ages 0–3 is administered under Part C of IDEA. In Missouri, a medical diagnosis of ASD for a child in this age range results in automatic eligibility for early intervention services up to age 3.

The process differs substantially for older children. Part B of IDEA defines students with disabilities as those children, ages 3–21, who have been properly evaluated by the public school and who meet the eligibility criteria under one or more of 13 educational categories. Autism is one of the 13 categories of education disability.

For the student to receive special education services, Part B of IDEA requires that the student meets the eligibility criteria under one or more of the eligibility categories specified in the law and demonstrates a need for special education services. Public schools do not *diagnose* students but instead determine *eligibility* for services. During the course of the educational evaluation to determine eligibility, educators draw upon information from a variety of sources and ensure that information obtained from these sources is documented and carefully considered. IDEA mandates that consideration be given to the results of evaluations from outside providers, but public schools are not required to accept the results or use them in program development. Sometimes this statement is misinterpreted to mean that educators do not have to accept the diagnosis of ASDs or other medical conditions. It is not the role of educators to challenge a medical diagnosis. However, a medical diagnosis alone is not sufficient to establish students' eligibility for

special education services if they are in the 3- to 21-year age range. Eligibility decisions are based on evaluation of child behaviors in the educational environment to determine if the child satisfies the criteria under an education category specified in IDEA, whether the condition adversely affects the child's educational performance, and whether the child needs special education services. If eligibility is met, assessment in the educational environment must be sufficient to guide development of an Individualized Education Program (IEP). The IEP addresses the unique learning needs of the child in the educational environment, which may be similar to or different from the needs of the child in other environments. The IEP is reviewed and revised at least once annually.

In some cases, students with ASD medical diagnoses may qualify for educational accommodations under a 504 Plan (Rehabilitation Act of 1973) even if they do not meet special education eligibility criteria in the Autism category. A 504 Plan establishes accommodations and modifications that can be integrated into the general education curriculum, such as extra time for test completion. This approach is an accepted practice for students with special needs who do not qualify for services under IDEA. Additional information can be obtained at [http://www.moddrc.org/fast\\_fact.php?disID=146](http://www.moddrc.org/fast_fact.php?disID=146).

Students who receive special education services based on criteria in the Autism eligibility category may or may not meet criteria for an ASD medical diagnosis and may or may not be eligible for other programs designed for individuals with disabilities.

#### **Assessment by Other Service Providers**

Other service providers typically utilize agency or organization-specific assessment procedures for eligibility determination and service planning. For example, eligibility for Department of Mental Health (DMH) services is based on state guidelines. Assessment is conducted to determine eligibility and to guide service provision for eligible individuals. DMH services typically require a medical diagnosis of an ASD and documentation of impaired adaptive functioning. Individuals who are eligible for DMH services may or may not be eligible for special education services. Other service agencies utilize their own internal eligibility standards and assessment procedures. Individuals who are determined to be eligible for other such services may or may not meet criteria for a medical diagnosis of an ASD and may or may not be eligible for special education services.

**COMPARISON OF ASSESSMENTS:  
CLINICAL/MEDICAL, EDUCATIONAL, AND OTHER SERVICE SYSTEMS**

TABLE 1.2

	CLINICAL/MEDICAL	EDUCATIONAL	OTHER SERVICES
<b>CRITERIA USED</b>	Medical Diagnostic Criteria based on <i>DSM-IV-TR</i>	Eligibility criteria established by federal law under the Individuals with Disabilities Education Act (IDEA) and state regulations as articulated in the <i>Missouri State Plan for Special Education</i>	Agency-based criteria
<b>EVALUATION PROCESS</b>	<p>Diagnostic evaluation is completed to determine if individual meets criteria for a medical diagnosis of ASD or another disorder.</p> <p>Re-evaluation is completed as indicated on a case-by-case basis.</p>	<p>Under Part C of IDEA in Missouri, children in the 0–3 year age range qualify automatically for First Steps early intervention services if they have a medical diagnosis of ASD.</p> <p>Under Part B of IDEA for students ages 3–21 years, evaluation for eligibility determination is completed to determine if student meets criteria under one or more of 13 education disability categories, including Autism.</p> <p>A need for reevaluation must be considered triennially but not more frequently than once a year unless the parent and school district agree otherwise.</p>	Eligibility evaluation to determine if individual meets agency's eligibility criteria
<b>ASSESSMENT PROCESS</b>	<p>May occur as part of or after diagnostic evaluation to identify individual strengths and concerns</p> <p>Results inform intervention across medical, educational, community, and home settings to minimize problems and maximize independent functioning.</p>	Assessment instruments are initially used as part of the evaluation for eligibility determination to identify areas in which a potential disability adversely affects the child's educational performance.	Results inform the individual's needs within the context of family priorities and resources.
<b>INTERVENTION PLANNING</b>	May include recommendations for medical treatment, medication management, outpatient speech-language, occupational and/or physical therapies, behavioral therapy, psychotherapy, family counseling and supports, educational strategies, and accessing community services	<p>Conducted by IEP team, of which parents are members</p> <p>The IEP addresses unique needs of the child and contains such items as annual goals, school-based services, environmental and instructional accommodations, and assistive technology. The IEP is reviewed and revised at least annually. A 504 plan may provide an alternative mechanism for classroom accommodations if a child does not meet eligibility for IEP services.</p>	Recommendations focus on specific agency services and other related resources that may be accessed.
<b>PLAN</b>	Treatment Plan(s)	<p>For 0–3 years, Individual/Family Service Plan</p> <p>For 3–21 years, Individual Educational Program</p>	Service Plan



### Integration of Plans and Programs

As Table 1.2 suggests, medical treatment plans, individualized educational programs, and service plans each contribute valuable information about the strengths and concerns of the individual with an ASD. These *Guidelines* recommend that professionals report findings from the assessments in a manner that facilitates usability across settings and allows families to synthesize this information into a comprehensive profile of the individual. If necessary, families have a variety of resources in Missouri that can assist with this process. Some of these resources are listed in Appendices E, H, and I.

### Continuous Monitoring and Evaluation

Assessment is a continuous process. Professionals and families continually work together to monitor changes in the presentation and symptoms of the individual diagnosed with an ASD. As changes are observed, new assessments may be initiated by either the family, lead clinician, or primary care provider. Points of transition require close monitoring (e.g., transition from Early Intervention services under IDEA Part C to special education services under IDEA Part B; from school to work or higher education) and often require reassessment to facilitate transition planning. Service coordinators in local Regional Offices within the Division of Developmental Disabilities, Department of Mental Health, can assist families in this way, or the lead clinician may help the family develop an integrated plan.

### Facilitation of Ongoing Care

Ongoing care for the individual and his or her family beyond ASD-specific services is critically important. Therefore, integral to the diagnostic and assessment processes is planning for follow-up services. This can take many forms. In some cases, the family is referred back to the PCP (if the PCP was not acting as the lead diagnostic clinician). The PCP, who is the lead healthcare provider close to the home of the individual with an ASD and her or his family, partners with the family to access services that meet the specific needs of the individual. The PCP is encouraged to continue ongoing consultation and collaboration with the lead diagnostic clinician and other specialty clinicians to address ASD-specific medical needs. At other times, follow-up is provided by the lead clinician. Regardless, careful and deliberate consultation with the family regarding their preferences for follow-up care is important.

## Implications for the Future of ASD Services in Missouri

Members of the Missouri Autism Guidelines Initiative and sponsors of this project believe that ASD screening, diagnostic, and assessment services can improve. This publication has been developed to enhance communication among professionals who work with individuals with ASDs and their families and to serve as a foundation for training parents, healthcare professionals, educators, and others in related best practices. Another publication, *Navigating Autism Services: A Community Guide for Missouri*, helps families understand the services available for people with ASDs, how to access these services, and where to start. Together these two publications provide a roadmap for families and professionals to access and improve ASD-related services. (See Appendix E for additional information on the *Navigation Guide*.)

# Screening for Autism Spectrum Disorders

## CHAPTER 2



## Introduction

During the past 10 years, significant advances in the development of screening instruments for autism spectrum disorders (ASDs) have led to an improved ability to accurately identify young children suspected of having ASDs. Early identification of ASDs is essential for a number of reasons. First, early detection promotes early intervention, which greatly increases the potential for improved developmental outcomes and reduced costs of care over time. This approach also helps parents understand and cope with their child's developmental concerns. Because of the critical importance of early identification, the American Academy of Pediatrics has recommended universal screening for ASDs at both 18 and 24 months of age (Johnson et al., 2007). Such a proactive policy of appropriate screening in Missouri will lead to timely referrals to clinicians capable of clarifying the individual's developmental difficulties and beginning early intervention (Farmer & Clark, 2008).

Numerous research studies have demonstrated that ASDs can be reliably and validly diagnosed by an experienced clinician in children as young as 18 months (Charman et al., 2005; Kleinman et al., 2008; Landa, Holman, & Garrent-Mayer, 2007; Lord, 1995; Pandey et al., 2008). These studies found that children with autism at age 2 years show distinct differences from typically developing children in social and communicative behaviors, including eye contact, coordination of eye gaze with vocalization or gesture, preverbal babbling, reciprocity in vocalizing or imitation, pointing to or showing of objects, and ability to follow another's focus of attention through eye gaze or gesture. The diagnosis of autism at age 2 has been shown to be relatively stable over time, although it is challenging to predict diagnostic stability for individual children (Kleinman et al., 2008; Webb & Jones, 2009). Many children experience the onset of symptoms of ASDs by 18 months, whereas symptoms in others are detected later. For instance, some children experience regression in developmental milestones between 18 and 36 months, and children with Asperger's Disorder typically are not identified until school age (Bryson et al., 2007; Landa et al., 2007; Williams et al., 2006).

A considerable body of research now focuses on clarifying the more subtle signs and symptoms of autism present at or before 18 months to aid in earlier detection (Brian et al., 2008; Wetherby et al., 2004). Advances have been made in identifying behavioral indicators as well as atypical development in very young children who are later diagnosed with ASDs. In a well-controlled study of infants, Clifford, Young, and Williamson (2007) reviewed home videotapes of infants' social behavior. Infants who were later diagnosed with autism showed less peer interest, gaze aversion, less anticipatory posturing, and little if any proto-declarative pointing. Zwaigenbaum and colleagues (2005) found that by 12 months, specific behavioral markers distinguished children with autism from children without autism. For example, atypical eye contact and visual tracking; disengagement of visual attention; lack of orienting to name; and the absence of imitation, social smiling, reactivity, and social interest were a few of the markers indicative of the presence of ASDs in the first year of life. Table 2.1 is a list of red flags designed for use by parents.

## RED FLAGS OF AUTISM SPECTRUM DISORDERS

TABLE 2.1

The following red flags may indicate that a child is at risk for an autism spectrum disorder and is in need of an immediate evaluation. If your baby shows two or more of these signs, please ask your pediatric healthcare provider for an immediate evaluation.

**IMPAIRMENT IN SOCIAL INTERACTION:**

- Lack of appropriate eye gaze
- Lack of warm, joyful expressions
- Lack of sharing interest or enjoyment
- Lack of response to name

**IMPAIRMENT IN COMMUNICATION:**

- Lack of showing gestures
- Lack of coordination of nonverbal communication
- Unusual prosody (little variation in pitch, odd intonation, irregular rhythm, unusual voice quality)

**REPETITIVE BEHAVIORS AND RESTRICTED INTERESTS:**

- Repetitive movements with objects
- Repetitive movements or posturing of body, arms, hands, or fingers

Red Flags are reprinted with permission from First Signs, Inc. For more information, please go to [www.firstsigns.org](http://www.firstsigns.org). First Signs is dedicated to the early identification of, and intervention for, children with autism and related disorders. Red Flags were compiled from the following source: Wetherby, A., Woods, J., Allen, L., Cleary, J., Dickinson, H., & Lord, C. (2004). Early indicators of autism spectrum disorders in the second year of life. *Journal of Autism and Developmental Disorders*, 34, 473-493. Based on research at the Florida State University FIRST WORDS® Project.

Other resources are available to help professionals and parents identify children with ASDs and related developmental concerns. For example, the Centers for Disease Control and Prevention (CDC) developed a public awareness campaign called *Learn the Signs. Act Early*. The program offers free materials that describe typical developmental milestones in young children, including social and emotional milestones. These materials focus on healthy development and can serve as a useful point of reference for all persons who are in contact with young children (see Appendix C for one of these resources). In addition, a free online *ASD Video Glossary* depicts key features of children who are developing typically compared to children diagnosed with ASDs across a number of different ages. These videos can help viewers clarify the distinctions between typical and atypical development. Website links for these online resources are included in Appendix E.

Unfortunately, in actual practice it has been difficult to reliably detect ASDs before the age of 3. The average age of diagnosis across the nation continues to be well past 3 years (CDC, 2007; Shattuck et al., 2009; Wiggins et al., 2006), often long after parents first express concern to physicians (Chawarska, Klin, Paul, & Volkmar, 2007; Interactive Autism Network [IAN] StateStats, 2009). This delay in diagnosis is even greater among children from racial/ethnic minorities and those who live in underserved regions such as rural communities (Mandell et al., 2009).

In part, this delay may be due to lack of awareness by healthcare and mental health providers about characteristic impairments in language and social skills in young children with ASDs and the need to screen specifically for this disorder. Early detection of ASDs also is

**BEST PRACTICE**

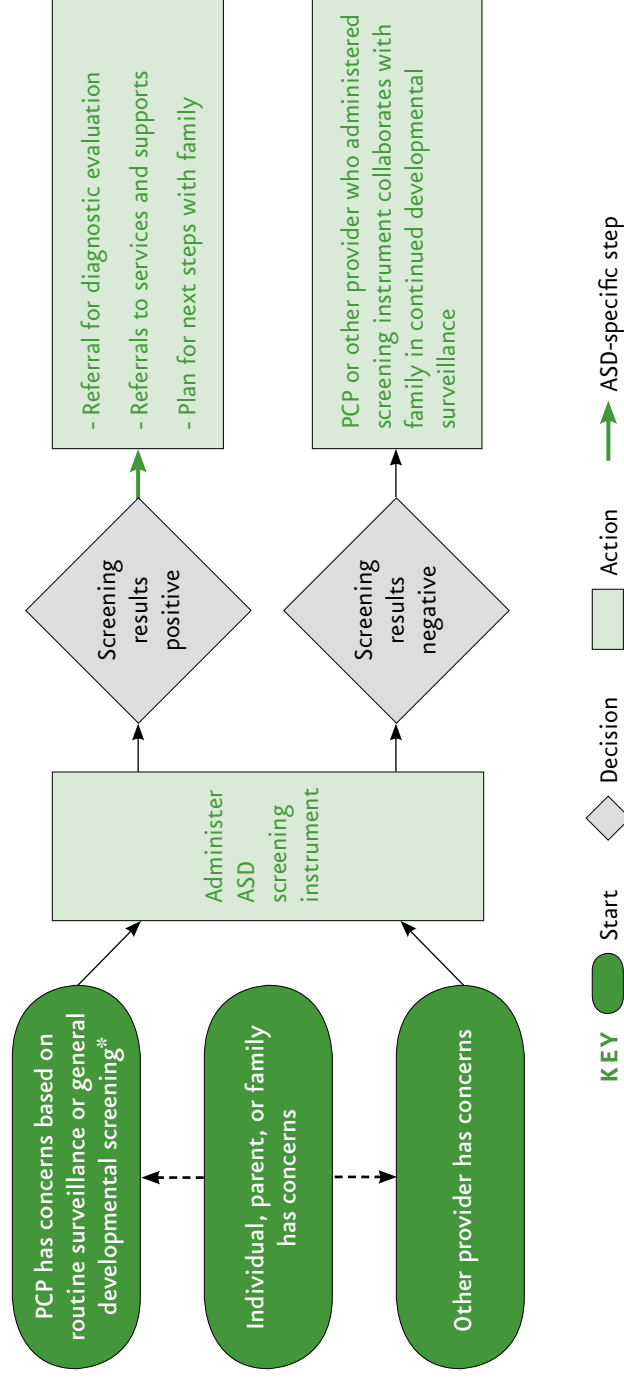
**All professionals involved in the care of young children are aware of developmental indicators of ASDs.**

challenging because existing diagnostic criteria are based on impairments in social, communication, and behavioral skills that may not be apparent in very young children. For instance, it is difficult to judge developmental deviation in peer relationships in children at 18 months, an age at which these skills would not be expected to have fully emerged. Finally, the detection of young children with ASDs is complicated by behavioral variation within the autism spectrum itself and the manifestation of symptoms at different ages. For example, children with Autistic Disorder are typically detected earlier than those with Asperger's Disorder because of the relatively intact early language and adaptive skills in the latter group.

Many studies have demonstrated, however, that early therapeutic intervention is associated with the best developmental, behavioral, and adaptive outcomes (Eikeseth et al., 2007; Howlin, 2008; Rogers & Vismara, 2008). Developmental screening and referral for evaluation are the critical first steps toward accurate diagnosis and assessment for intervention planning (see Figure 2.1).

## DEVELOPMENTAL SCREENING AND REFERRAL FOR EVALUATION

FIGURE 2.1



\* Routine screening by Primary Care Provider (PCP) is recommended at 18 and 24 months

The remainder of this chapter is organized into the following sections:

- Community Collaboration
- Screening in Young Children
  - The Role of the Primary Care Provider
  - The Role of Other Professionals
  - The Role of Parents
- Screening in Older Children, Adolescents, and Adults
- The Referral Process

## Community Collaboration: A Key to Early Detection

Early detection of ASDs requires that all professionals working with young children engage in developmental surveillance, or the routine monitoring and tracking of developmental milestones. This ongoing process typically occurs at well-child visits with primary care providers (PCPs), especially for young children. However, developmental surveillance is also conducted by specialty care providers, educators, and other community professionals with expertise in child development. For children who show any of the red flags for ASDs, surveillance leads to screening and an appropriate referral for diagnostic evaluation. The professional offers ongoing support and information to the family, and parents are included as full partners in this process.

Parents often prompt closer developmental surveillance if they have concerns about their child. Parents may speak with their child's PCP or other healthcare provider, a First Steps Service Coordinator, a parent educator from Parents As Teachers, child care providers, school nurses, or teachers about these concerns. Professionals should respond by either conducting or referring the child for an ASD screening and considering referral for a full diagnostic evaluation if indicated by the parent's concerns. Effective communication and collaboration among professionals are essential for early detection of ASDs, given that families must have adequate supports to successfully navigate the system of care during this process.

### BEST PRACTICE

**All professionals responsible for the care of children perform routine developmental monitoring to identify children with atypical development.**



# Screening in Young Children – Birth to Five

## THE ROLE OF THE PRIMARY CARE PROVIDER IN EARLY IDENTIFICATION

The importance of the PCP in developmental surveillance and screening cannot be over-emphasized. The successful identification of ASDs in young children and the effectiveness of intervention programs depend on the ability of PCPs to monitor children's development and initiate referrals in a timely manner. The American Academy of Pediatrics (AAP, Johnson et al., 2007) recommends a three-step process for the detection of young children with ASDs: (a) routine developmental surveillance; (b) general developmental screening at 9, 18, and 30 months; and (c) ASD-specific screening at 18 and 24 months.

### Developmental Surveillance and General Screening

Primary care providers are often the first point of contact for parents with concerns and questions regarding their child's development. Parents expect their PCPs to offer guidance regarding developmental issues. Well-child visits are the logical time and place for developmental surveillance and screening to occur.

According to the American Academy of Pediatrics (Council on Children With Disabilities, 2006), there are five components of developmental surveillance and screening:

1. eliciting and attending to the parents' concerns about their child's development;
2. documenting and maintaining a developmental history including parent observations, professional judgments, and tracking of developmental progress as compared with children of similar age;
3. making accurate observations of the child's development by screening with reliable standardized instruments;
4. identifying risk and protective factors; and
5. maintaining and sharing an accurate record of the findings.

There are noteworthy clinical signs that can help identify children at risk for developmental delay and/or ASDs. These indicators typically are tracked through routine developmental surveillance, which should occur at all well-child visits. The signs most frequently identified in infants and toddlers at risk for ASDs are delays in language and social-emotional responding. However, "red flags" can also include more subtle differences that should trigger further specific screening for ASDs (see Table 2.1). These include:

- not turning when parents say the child's name;
- not turning to look when the parent points saying, "Look at ...";
- not pointing across a room to show parents an interesting object or event;
- lack of back-and-forth babbling;
- smiling late; and
- failure to make eye contact.

Formal screening for general developmental delays using standardized instruments is recommended at the 9-, 18-, and 30-month well-child visits (AAP Council on Children with Disabilities, 2006). The 24-month well-child visit is also an accepted time for general screening. Examples of commonly used general screening instruments are listed in Appendix D-1, and these measures typically assess developmental milestones in domains such as language, gross and fine motor skills, and cognitive or problem-solving skills. It is important to note that these measures are not designed to detect specific symptoms of ASDs. The most powerful indicator of an ASD based on these instruments is degree of language development. Any child not using single words by 16 months of age or some two-word phrases by 2 years of age should be further evaluated. Children who do not use gestures (e.g., pointing, waving, etc.) or who cannot follow gestures and other nonverbal communication by 12 months are also at risk. If such concerns or other red flags are identified, follow-up with a specific ASD screening instrument should be conducted (see Table 2.2).

Finally, any unexpected loss of language or delay in social milestones prior to the age of 3 years is a serious red flag and warrants a referral for further evaluation, as this may represent a regressive form of autism (Filipek et al., 2000; Rogers, 2004). In older children, loss of language or social skills that are not regained through typical interventions also should be evaluated further. Siblings of children with ASDs are at higher risk for the disorder, as are young children who show general developmental delays. These children should receive more intensive monitoring and screening.

### ASD Screening

In addition to ongoing developmental surveillance and general screening, the American Academy of Pediatrics has recommended specific ASD screening of all infants at ages 18 and 24 months (Johnson et al., 2007). Screening at these two periods is recommended because most children who are later diagnosed with ASDs display a failure to achieve core communication and social milestones and atypical behaviors by the second year of life (Brian et al., 2008; Webb & Jones, 2009). Because some children with ASDs evidence regression in skills between 15 and 21 months (Bryson et al., 2007; Landa et al., 2007), screening at age 2 years facilitates identifying these children as well. *This is not to suggest that concerns noted earlier by parents or other professionals should be dismissed until this time.* Optimally, developmental screening specific to ASDs will occur at any point at which routine surveillance and/or child observations indicate it is warranted.

Most screening instruments appropriate for ASDs are brief and can be completed in the healthcare provider's waiting room. A list of commonly used ASD screening instruments is found in Table 2.2. The *Modified Checklist for Autism in Toddlers (M-CHAT)* is available free of charge online in many different languages. The *M-CHAT Follow-up Interview*, which is strongly recommended, is also available without charge at the same website. Copies of the *M-CHAT* (both English and Spanish versions) are provided in Appendix D-2.

#### BEST PRACTICE

Higher risk children are given more intensive monitoring and screening.

#### BEST PRACTICE

At a minimum, specific screening for ASDs occurs for all children at 18 and 24 months of age.

## ASD SCREENING INSTRUMENTS

TABLE 2.2

SCREENING INSTRUMENT	<i>Modified Checklist for Autism in Toddlers (M-CHAT) &amp; Follow-Up Interview</i>	<i>Social Communication Questionnaire (SCQ)</i>
ASD SYMPTOMS ASSESSED	Measures protodeclarative pointing, response to name, interest in peers, showing objects of interest to parents, imitation, responding to others pointing	Designed to identify children at risk for autism from the general population; based on items in the <i>Autism Diagnostic Interview-Revised (ADI-R)</i>
AGE RANGE	16–48 months	4 years and older (mental age of at least 2 yrs)
FORMAT	Parent questionnaire  Practitioner interview for structured follow-up on failed items	Parent questionnaire: Lifetime & Current Versions
NUMBER OF ITEMS AND COMPLETION TIME	23 yes/no items  5–10 minutes	40 yes/no items  10 minutes
CLINICIAN TIME	Questionnaire scoring: 2 minutes Follow-Up Interview: 5–20 minutes	Less than 5 minutes
SCORING INTERPRETATION	Risk categorization (pass/fail)	Risk categorization (pass/fail)
SENSITIVITY	85%	85%
SPECIFICITY	91–99%	75%
WEBSITE	<a href="http://www.mchatscreen.com">www.mchatscreen.com</a>	<a href="http://www.wpspublish.com">www.wpspublish.com</a>
AUTHORS	Robins, Fein, & Barton, 1999	Rutter, Bailey, & Lord, 2003
COST OF BASIC KIT	Free online	\$104.50

<b><i>Social Responsiveness Scale (SRS)</i></b>	<b><i>Childhood Autism Spectrum Test (CAST)</i></b>	<b><i>Pervasive Developmental Disorders Screening Test-II, Primary Care Screener (PDDST-II PCS)</i></b>
Measures social awareness, social information processing, reciprocal social communication, social anxiety, autistic traits and preoccupations	Designed to assess more <i>subtle</i> forms of impairment with regard to socialization, communication, and behavior in school-age children (e.g., peer relationships, conversational skills, intense areas of interest)	Designed to identify children at risk for autism from the general population; measures social interactions, communication, and atypical behaviors
4–18 years	4–11 years	12–48 months
Parent and/or teacher questionnaire	Parent questionnaire	Parent questionnaire
65 items (1–5 rating scale)	37 yes/no items	22 yes/no items
15–20 minutes	10 minutes	10–15 minutes
5–10 minutes	5 minutes	5 minutes
Quantitative measure of symptom severity; a cutoff score can be used for risk categorization	Quantitative measure of symptom severity; a cutoff score can be used for risk categorization	Risk categorization (pass/fail)
75–90%	74–100%	85–92%
80–96%	93–99%	71–91%
<a href="http://www.wpspublish.com">www.wpspublish.com</a>	<a href="http://www.autismresearchcentre.com">www.autismresearchcentre.com</a>	<a href="http://www.pearsonassessments.com">www.pearsonassessments.com</a>
Constantino & Gruber, 2005	Scott, Baron-Cohen, Bolton, & Brayne, 2002	Siegel, 2004
\$91.00	Free online	\$155.33

All screening instruments have their limitations, but the PCP should choose and become familiar with an ASD screening instrument for each age group and use it consistently. For infants and very young children, general developmental screening instruments that evaluate social and communication skills may assist in systematic detection of early signs of ASDs (see Appendix D-1).

A number of strategies are available to support the accuracy of ASD screening results. For example, the *M-CHAT Follow-up Interview* provides an algorithm for review of each failed item, requesting that the parent provide specific examples of concerning behaviors. This brief process provides the PCP with rich detail about parental observations to help clarify the best response to each item. In addition, the PCP can structure simple activities that allow direct observation of atypical behaviors during the course of an examination (e.g., calling the child's name to see if he or she responds, requesting that the child imitate gestures and follow a point to an object across the room, providing opportunities to share enjoyment during a simple game, or engaging in pretend play). Although often informative, this approach may yield false positives among children who are anxious in medical settings. Both parental and PCP observations should be given due consideration during the screening process. If either the parent or the PCP has persistent concerns, the child should be considered at risk and referral for further evaluation should be made.

*A positive ASD screening indicates that the child shows signs of a developmental concern compared to other children in the same age range. However, a positive screening does not mean the child will meet criteria for an ASD diagnosis. Immediate referral for further evaluation is necessary to clarify the child's developmental strengths and concerns, identify the most appropriate diagnosis, and recommend intervention strategies. Watchful waiting is not appropriate when there is a positive screen. Recommended referral strategies are discussed on pages 39-40.*

#### BEST PRACTICE

A positive screening results in an immediate referral for further evaluation of developmental concerns.

#### Implementing Screening Practices

Although the American Academy of Pediatrics Practice Guidelines (Johnson et al., 2007) and the federal and state Early and Periodic Screening, Diagnosis and Treatment (EPSDT) schedules recommend routine developmental monitoring at well-child visits, numerous studies have shown that standardized screening does not occur in most healthcare practices (Dosreis, Weiner, Johnson, & Newschaffer, 2006; Sand et al., 2005). This is despite the fact that physicians identify only a small percentage of children with developmental concerns if they do not systematically use screening instruments (Robins, 2008). In practice, time constraints often hinder routine developmental screening, and parents often do not voice developmental concerns unless specifically elicited by the PCP (Glascoe, 2003). In addition, some children are seen only in emergency rooms or urgent care clinics for health care, particularly after the age of 2 when the immunization schedule is diminished. When screening does occur, measures used are at times insensitive to communication and social milestones in young children and may miss children with ASDs or less obvious developmental delays (Webb & Jones, 2009).

Studies have shown that even when parents bring up developmental concerns, some PCPs respond by waiting to see if the delays will resolve spontaneously or by discounting parental observations. They may be unaware of the high degree of accuracy often associated with parents' concerns regarding their child's development (Glascoe, 2003). Although a small number of children do "catch up" without formal intervention and achieve developmental milestones somewhat later than same-age peers, this is the exception. A significant number of children require early intervention either on a transient or an ongoing basis to function within their family and community environment. Furthermore, those children who turn out to be "false positives" (parental concerns are expressed, but the child has no clinically significant delays) tend to score somewhat lower on developmental domains than those children who are true "negatives" (parents have no concerns, and the child demonstrates typical development; Glascoe, 2001).

Research efforts have demonstrated that screening is manageable within current primary care practice parameters in terms of time and cost (Sasso, 2001). Health insurers generally reimburse healthcare providers for administering developmental and ASD-specific screening instruments. *Developmental screening tests, including ASD-specific tests that are completed by a parent or non-clinician staff member and are reviewed and interpreted by the healthcare provider, can be billed using CPT code 96110.* Other valuable information about successful screening practices is summarized in online materials designed for healthcare professionals (see Appendix E).

The following two case examples illustrate the use of an ASD screening instrument in a primary care practice to guide clinical decision making. The first example shows how a pediatrician determines that the child is at low risk for developmental concerns, and the second example describes the identification of a child who needs further evaluation.

# Screening Case Examples

## CASE EXAMPLE #1: PRIMARY CARE

### SCREENING RESULTS DO NOT INDICATE NEED FOR DIAGNOSTIC EVALUATION

*Ryan is a 24-month-old boy whose mother completed the Ages & Stages Questionnaire-3 (ASQ-3) and the Modified Checklist for Autism in Toddlers (M-CHAT) as part of his well-child check with Dr. Jones, his pediatrician. Recently, the pediatrics practice adopted a policy of asking all parents to complete an autism screening in addition to general developmental screening at both the 18- and 24-month well-child visits.*

Ryan has been generally healthy except for frequent ear infections. His motor and language milestones have been reached on time. For instance, he sat without support at 6 months, walked at 12 months, and said his first words at 13 months. He does not have siblings and is not in a child care program.

When the family arrived for Ryan's appointment, the front desk staff gave the mother the ASQ-3 and M-CHAT screening forms to complete in the waiting area, assuring her that these were short and would not take long to finish. Soon the nurse called Ryan's name and greeted the mother. The nurse also collected the ASQ-3 and M-CHAT forms and scored them for Dr. Jones to discuss during the visit. The ASQ-3 was within normal limits, but two of the six critical M-CHAT items were failed, suggesting possible concern for an autism spectrum disorder ("Takes interest in other children" and "Responds to name" were answered "No"). Dr. Jones used the M-CHAT Follow-up Interview as a method to clarify the mother's observations in the two failed areas.

The interview revealed that Ryan does not have many opportunities to interact with other children. However, he smiles at other children at the grocery store and sometimes points and comments with words like "boy." Currently, he uses two-word phrases in many situations to interact with others, such as requesting what he needs. At the playground, he likes to dump sand into a bucket with other children and laughs with them when it spills. His mother noticed that Ryan has not been responding to his name in the last day but added that this behavior is unusual for him. She commented that Ryan has been pulling at his ears and running a low-grade fever. Otherwise, she did not report any concerns about her child.

Past medical history was unremarkable, and the physical examination revealed no dysmorphic features or other signs of a genetic disorder. During the exam, Dr. Jones observed that Ryan made good eye contact and followed her point to a toy in the room. When she handed the toy to him, Ryan smiled at her while shifting his gaze from the toy to her face as she smiled back. Ryan then pointed at the sink and asked for a drink.

Dr. Jones diagnosed Ryan with a left acute ear infection and fluid in his right ear. She explained to the mother that children with frequent ear infections could develop fluid in their ears with secondary hearing loss. Dr. Jones prescribed medications to treat the acute ear infection. Dr. Jones instructed the mother to schedule a follow-up visit in 10 days to recheck the ears. She informed the mother that Ryan appeared to be developing normally compared to other 2 year olds and provided her with handouts on typical social and emotional development from the CDC *Learn the Signs. Act Early* program. She also provided the mother with information about the Parents As Teachers program in her area, explaining that this program helps parents understand and encourage healthy development in their young children. Finally, Dr. Jones scheduled a subsequent well-child visit when Ryan was 30 months old to administer another general developmental screening measure and a follow-up M-CHAT.



## CASE EXAMPLE #2: PRIMARY CARE

### SCREENING RESULTS INDICATE THE CHILD SHOULD BE REFERRED FOR DIAGNOSTIC EVALUATION

*John is a 24-month-old boy whose mother completed the Ages & Stages Questionnaire-3 (ASQ-3) and the Modified Checklist for Autism in Toddlers (M-CHAT) as part of his well-child check with Dr. Jones, his pediatrician. Recently, the pediatrics practice adopted a policy of asking all parents to complete an autism screening in addition to a general developmental screening at both the 18- and 24-month well-child visits.*

John has been generally healthy except for frequent ear infections. His motor and language milestones have been reached on time. For instance, he sat without support at 6 months, walked at 12 months, and said his first words at 13 months. He does not have siblings and is not in a child care program.

When the family arrived for John's appointment, the front desk staff gave the mother the ASQ-3 and M-CHAT screening forms to complete in the waiting area, assuring her that these were short and would not take long to finish. Soon the nurse called John's name and greeted the mother. The nurse also collected the ASQ-3 and M-CHAT forms and scored them for Dr. Jones to discuss during the visit. The ASQ-3 showed that the mother had significant concerns regarding John's development in the Communication domain. In addition, two of the six critical M-CHAT items were failed, suggesting possible concern for an autism spectrum disorder ("Takes interest in other children" and "Responds to name" were answered "No"). Dr. Jones used the M-CHAT Follow-up Interview as a method to clarify the mother's observations in the two failed areas.

The interview revealed that John has many opportunities to interact with other children, given that he has numerous cousins in the area. However, in the last 6 months, John has seemed to lose interest in playing with his cousins, preferring to play by himself with spinning toys. He has also stopped responding to his name consistently, which made the mother think that he may not be hearing. She was worried about changes in his behavior, saying that he seemed to be in his own little world. Further questioning revealed other concerns. For example, John wasn't talking as much since their last visit to the doctor and mostly echoed what others said to him. He had been a good eater, but now he eats only chicken nuggets and one kind of cracker that she buys at a specialty store. If she tries to give him something else, he falls on the floor, hits himself, and cries for up to 1 hour.

Past medical history was unremarkable. During the physical examination, Dr. Jones observed that John made very poor eye contact and did not speak. He did not follow her point to a toy in the room. When she tried to hand the toy to him, John looked away and preferred to flick the light switch in the room repetitively. He covered his ears after hearing a noise in the hallway, but he did not respond to his name or to other verbal requests despite multiple attempts by Dr. Jones and his mother. John was otherwise healthy, with a normal physical exam and normal growth percentiles.

After listening to the mother's concerns, Dr. Jones described her own observations to the mother and noted that she agreed with the mother's concerns. She recommended a full evaluation to further clarify John's developmental strengths and concerns, mentioning that autism spectrum disorders might be considered. However, she added that changes in John's behavior could be due to other developmental challenges and underscored that the diagnostic clinician would help them determine the nature of the problems and suggest treatment. Dr. Jones explained that further evaluation by the diagnostic

(CONTINUED)

(CONTINUED)

clinician would likely include a detailed interview about John's development along with direct observation of John's social interaction, language, and other skills.

Dr. Jones gave the mother a chance to respond to this information, answered her questions, and assured the mother that she would provide follow-up and support over time. John's mother agreed that the evaluations would be helpful in monitoring John's development and determining the appropriate intervention, if necessary. Dr. Jones gave the mother a small packet that included a copy of John's *M-CHAT* screening results to take to the diagnostic clinician; the CDC *Learn the Signs. Act Early.* materials on typical child development; a brochure about the Parents As Teachers (PAT) program; and a brochure from the Office of Autism Services titled, *Could My Child Have Autism?* She informed the mother that PAT is a free community service through the local school district and that the parent educator could provide fun activities to support John's development at home. She asked her nurse to help the mother set up a hearing evaluation, a speech and language evaluation with a local provider, and the specialized developmental evaluation. Finally, Dr. Jones requested a follow-up appointment within 2 months to review John's progress and discuss available evaluation results. She also instructed the mother to email her with any questions or concerns.

### THE ROLE OF OTHER PROFESSIONALS IN EARLY IDENTIFICATION

Not every child with signs of an ASD will be identified by the PCP. In a recent survey, only 8 percent of pediatricians screened for ASDs (Dosreis et al., 2006). Other community professionals play a critical role in identifying, referring, and following up with young children at risk for ASDs. Such professionals include:

- specialty care physicians, including hospitalists;
- Missouri First Steps Early Intervention providers;
- Parents As Teachers (PAT) parent educators;
- speech-language pathologists;
- school personnel in public school districts;
- child care providers;
- nurses, including those in schools and public health settings;
- licensed clinical social workers;
- Child Protective Services personnel and other social service agency staff;
- community mental health professionals;
- occupational and physical therapists;
- audiologists;
- school resource officers and others in the juvenile justice system;
- Missouri Division of Developmental Disabilities service coordinators; and
- Missouri Bureau of Special Health Care Needs service coordinators.

These front line professionals frequently interact with young children, and they should be prepared to support parents through ASD education and outreach training. For instance, they should be aware of the common "red flag" indicators of ASDs, know how to talk with parents about their observations, and know how to refer families to appropriate resources for additional supports. The following section presents examples of the agencies and individuals engaged in screening in community settings.

### **First Steps Program Providers** <http://www.dese.mo.gov/divspeced/FirstSteps/index.html>

The Missouri First Steps program is designed for infants and toddlers, birth to age 3, who have delayed development or diagnosed conditions that are associated with developmental disabilities. Professionals in the First Steps program are immediately available to discuss parental concerns about developmental differences, conduct screening for social and emotional development and ASDs, and make the necessary referrals. In addition, First Steps provides a variety of early intervention services for children who meet eligibility criteria. Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) are among the medically diagnosed conditions that lead to automatic eligibility in First Steps.

### **Parents As Teachers Parent Educators** <http://www.parentsteachers.org>

Because parental influence in the child's life is so important, Parents As Teachers (PAT) offers a strong program of parent education for all families of young children. The parent education program offers home visits by a certified parent educator, monitoring of children's general development, and a resource network for young families. Parent educators screen for developmental disorders, including social and emotional concerns, and they provide information regarding ways to encourage healthy development at home.

### **Speech-Language Pathologists**

Speech-language pathologists play a critical role in the early identification of children with ASDs because delays in speech and language development are often the initial area of concern. Sometimes referred to as speech therapists, these professionals possess training specific to the development of social skills, communication, and behavior, the areas affected by ASDs. Speech-language pathologists are found within school systems, hospitals and clinics, the Missouri First Steps program, and a variety of private settings. As part of routine observation in these various environments, they are trained to detect atypical development and to differentiate ASDs from other developmental disorders. Speech-language pathologists are an important resource during the processes of screening, assessment, and intervention.

### **School Personnel**

Children with ASDs may initially be identified as having educational difficulties; therefore the role of school personnel in early identification has increased significantly with increases in the prevalence of ASDs. School settings offer many opportunities for routine monitoring of educational performance and observation of social and emotional development. School personnel are in a unique position to contribute to ASD detection, especially for children who are missed during well-child visits in healthcare settings (e.g., older children with less severe symptoms). ASD monitoring and screening may take place in several different ways in school settings, as described below.

**General developmental screening.** School personnel typically screen all children in multiple developmental areas prior to entry into kindergarten, including the areas of communication and social and emotional development in which delays may be associated with ASDs. If positive, this general screening typically leads to further monitoring and/or evaluation in the school setting. Parents are fully involved in this process and must provide written consent.

**Coordinated Early Intervening Services (CEIS).** If a child is experiencing difficulty functioning in the school environment or progressing in the general curriculum, the school may initiate Coordinated Early Intervening Services (CEIS). CEIS refers to the best practice of intervening with specific teaching/learning strategies and/or environmental supports at the first sign that a student is struggling or falling behind same-aged peers. This process is a function of regular education and can range from standardized screening measures to direct interventions. The process involves the parent in discussion and decision making from the onset and occurs prior to consideration of a referral for special education eligibility. If a

referral is later warranted, data on the effectiveness of various intervention strategies are considered as a component of eligibility determination. For more information about the CEIS process, see Appendix J.

**Evaluation for special education services.** ASD screening instruments may be used to help guide the course of formal evaluation for special education eligibility. This process is carefully regulated by the *Missouri State Plan for Special Education* (DESE, 2007); therefore, an educator cannot simply choose an instrument like the *M-CHAT* and administer it to an individual child. Rather, formal evaluation procedures must be initiated with written parental consent. The Educational Screening Case Example on page 38 illustrates how an ASD screening instrument might be used during the educational evaluation process.

The role of the school psychologist in this process has been more clearly defined in recent years (Brock, Jimerson, & Hansen, 2006; Noland & Gabriels, 2004). School psychologists are expected to possess the competencies and skills needed to accurately identify features of ASDs in school-age children. They work as part of the school's evaluation team to ensure that each child's needs are identified during the evaluation for special education eligibility and are addressed in the Individualized Education Program (IEP) if the child is determined eligible. They also provide a "bridge" that supports effective communication among parents, healthcare providers, and educational teams during the diagnostic, assessment, and treatment planning processes.

If school staff observes indicators of a possible ASD or if a child meets IDEA eligibility for special education services under the categorical label of Autism, further discussion needs to occur with the parents to help them understand the different resources available to them through the educational and medical systems. Because educational professionals do not provide a medical diagnosis of an ASD, the benefits of a diagnostic medical evaluation should be explained and parents encouraged to speak with the child's PCP or with a lead diagnostic clinician. Possible benefits for the child and family include access to ongoing medical treatment and monitoring, access to supports and interventions from community-based service providers to address challenges the child and family may experience at home and in the community, possible insurance benefits, and possible future eligibility for support services as an adult with an ASD. The special education team also benefits from information contained in a comprehensive clinical report by health professionals because it may further inform appropriate interventions and supports in the school environment.

#### BEST PRACTICE

When indicators of ASDs are observed in the school setting, educational personnel discuss with parents the potential benefits of a diagnostic medical evaluation.

#### Nurses

The role of pediatric nurses and nurse practitioners is becoming more important for establishing routine screening practices (Nadel & Poss, 2007; Pinto-Martin, Souders, Giarelli, & Levy, 2005). Nurses are being recognized as potential leaders in ASD screening. They are able to conduct routine developmental screenings using validated instruments while performing other duties during well-child clinic visits. In addition, nurses working in schools and public health settings are in an excellent position to detect at-risk children.

#### BEST PRACTICE

School and community professionals are adequately prepared to assure timely screening, referral, and diagnosis of persons with ASDs.

To promote the best outcomes for children and families, school and community-based professionals must work together to ensure early identification of ASDs, referral for diagnostic and assessment services, and rapid access to treatment.

## THE ROLE OF PARENTS IN EARLY IDENTIFICATION

Because parents are the experts regarding their children, eliciting and valuing parental concerns is imperative. Research demonstrates that most parents of children with ASDs expressed concerns regarding their children's development before 18 months of age. A recent multisite survey of the age of diagnosis revealed that there is a large gap between the age at which children can be accurately identified and when they actually are identified (Shattuck et al., 2009). This CDC-sponsored study found that the median age of identification was 5.7 years, which is 3 to 4 years after an accurate diagnosis is possible. A lengthy and cumbersome referral and diagnostic process contributes to considerable parental anxiety, places unneeded stress on parents and families, and squanders valuable intervention time.

Research has supported the notion of parental accuracy with regard to developmental concerns in their child (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Ozonoff et al., 2009). The majority of parents of children with ASDs notice abnormalities during the course of the first 2 years of life. With the documented efficacy of early intervention in achieving optimal outcomes for young children and their families, it is imperative that all concerns be taken seriously and addressed appropriately.

All professional encounters with young children should be viewed as an opportunity to elicit developmental information from parents. This includes visits with PCPs, child care providers, school officials, and teachers, to name a few. Elicitation of parental concerns could occur at any appropriate family encounter: well-child visits, sick-child visits, or other therapy appointments. Child care providers and school staff should make it a practice to ask parents and caregivers periodically about issues regarding their children's development and provide credible information on expected development.

Parents' inquiries regarding their child's development should be responded to at every visit. Expression of any concern by the parent is grounds for follow-up procedures. If warranted, follow-up could be pursued at that time or at a subsequent appointment with further parent discussion, more standardized paper-and-pencil tools, and/or direct child observation, if indicated. The choice of follow-up methodology is made at the discretion of the professional. However, parents should persist in expressing their concerns, even requesting developmental screening or sharing results from online ASD screening measures, if necessary.

Following up on parental concerns is important; however, screening should not be done only in response to a parental concern. Many parents do voice concerns regarding their children to professionals in the community, but this is not always the case. Some parents may not be able to articulate their observations. This is especially true with ASDs in which early social signs are subtle. Other parents may simply not notice developmental problems or may not view them as cause for concern because of other environmental and cultural factors.

This section has discussed the typical age range for screening for ASDs, which is birth through 5 years, but screening can extend to older children and even into adulthood. For children with milder forms of ASDs, identification and diagnostic confirmation can sometimes occur well after 6 years of age. As greater public awareness of the signs of ASD has increased in the general population via the media, Internet, support groups, and other forms of information sharing, more adolescents and adults are being identified and diagnosed with ASDs.

### BEST PRACTICE

**Community professionals elicit and respond to parents' concerns about their child's development and behaviors at every healthcare provider contact, including well- and ill-child visits.**

### BEST PRACTICE

**Parents are included as full partners throughout the screening and referral processes.**

## Screening in Older Children, Adolescents, and Adults

The screening process for individuals ages 6 and older who are suspected of ASDs is somewhat different from the process for younger children. Routine screening for ASDs is no longer the norm in this age group. Yet the question of ASDs may still be raised due to parental, family, educator, and/or the individual concerns regarding social and communication impairments and atypical behaviors. Compared with younger children, individuals who are age 6 and older are likely to demonstrate difficulties with peer relationships in marked contrast to same-age peers. Opportunities to observe children in the social and learning environment at school may call attention to symptoms of ASDs that were missed or misdiagnosed previously. Sometimes ASDs in young adults are identified as they enter college or the workplace.

Failure to identify a child prior to age 6 may be related to the following factors:

- The child was not detected prior to the age of 6 because of issues of access; lack of awareness regarding developmental norms; and demographic, cultural, and/or family factors. Some children do not have access to a PCP or to developmental monitoring by professionals familiar with the symptoms of ASDs because of either geographic location or financial barriers to care. Some families may be aware of developmental differences in their child but choose to avoid the screening and referral processes because of the perceived stigma of the diagnostic label and a lack of knowledge about the potential effectiveness of interventions. Other families may be highly tolerant of atypical behaviors, overwhelmed by extreme psychosocial stressors, or have cultural beliefs that discourage access to professional services.
- The child was identified with another *DSM-IV-TR* diagnosis such as Mental Retardation, Language Disorder, Obsessive Compulsive Disorder, or Attention Deficit Hyperactivity Disorder, but symptoms of ASDs were overlooked.
- The child is high functioning (i.e., intact language, intellectual abilities, academic performance and adaptive skills) but with increasing age displays marked social impairments and behavioral difficulties relative to peers. For example, children with Asperger's Disorder are typically identified for assessment relatively late in their development. Their limitations go unnoticed or are not perceived as impairing until demands for social and communicative competence increase. Furthermore, because the diagnosis of Asperger's Disorder was not introduced in the DSM until 1994, many individuals with this disorder have been diagnosed as adults.

Because routine developmental screening is not generally conducted after entry into kindergarten, ongoing developmental surveillance by healthcare professionals and educators continues to be key for the identification of ASDs in school-age children. This requires that professionals be familiar with reasons that children are missed as well as symptoms that might make them suspect ASDs among children in this age range.



ASD screening instruments designed for young children such as the *M-CHAT* are not particularly useful in this age group. However, several screening tests are available for use with older children and adolescents up to age 18 (see Table 2.2). For instance, the *Social Communication Questionnaire* (SCQ; Lifetime and Current Versions) is a parent report screening instrument based on the *Autism Diagnostic Interview-Revised*. The Lifetime Version assesses the presence of symptoms of ASDs over time, and the Current Version examines the child's symptoms at the time of screening. Another measure, the *Social Responsiveness Scale* (SRS), is unique in that it assesses both the presence and the extent of symptoms of ASDs, measuring the severity of social impairment and capturing even milder symptoms in this domain. These screening instruments can be a valuable source of information regarding a young person's behavior, communication skills, and social skills relative to same-age peers. For this reason, it is recommended that standardized instruments be utilized by PCPs or other front line service providers when school-age children are screened for ASDs.

Unfortunately, specific Asperger's Disorder screening instruments in the 6–22 age group have yet to demonstrate adequate reliability and validity (Campbell, 2005). Thus, developmental monitoring and routine surveillance may be the primary alternative for older children and young adults who are higher functioning and suspected of having Asperger's Disorder. However, screening instruments such as the *Childhood Autism Spectrum Test* (CAST) or the SRS can be used to guide developmental surveillance efforts.

Given the relative weaknesses in ASD screening instruments for older children and young adults, professionals may wish to consider multiple sources of information across environments prior to referral, including screening results, behavioral observations, history provided by parents, and/or records about the child's developmental trajectory. If an ASD is suspected, the individual should be referred immediately for full diagnostic evaluation and assessment for intervention planning.

The following case example illustrates the use of an ASD screening instrument in a school setting to help identify an older child at risk for ASDs. Although ASD screening may help guide school-based assessments that determine the eligibility category for special education services, this case also points out that additional evaluation by healthcare professionals is required for consideration of a medical diagnosis of ASDs.

#### BEST PRACTICE

**If developmental screening suggests an ASD, there is an immediate referral for further evaluation regardless of the age of the individual.**



# Screening Case Example

## CASE EXAMPLE #3: EDUCATIONAL SCREENING

### INDIVIDUAL EDUCATION PROGRAM TEAM INITIATES SCREENING

*Joe is a 12-year-old student who has received special education services since entering school. He was evaluated and determined eligible for services in kindergarten as Language Impaired. He began receiving additional special education services for reading and written expression in second grade. Joe receives services based on eligibility in the Learning Disabilities category and is educated for most of the day with his typically developing peers. He spends the other part of the day in a classroom designated for students with disabilities, where he receives support with study skills, organizational planning, social skills, and pragmatic language.*

Joe's Individual Education Program (IEP) team agrees that he needs special education and related services, but some members of the team, including Joe's parents, believe his behaviors may reflect a condition other than a learning disability or language impairment. Joe keeps to himself most of the day, quietly completing assignments. Although he now readily engages others in conversation, he tends to spend time talking about limited topics (dinosaurs and monsters). Joe willingly completes most assignments, especially if he can earn a dinosaur sticker for correct answers. The teacher describes Joe as a child who seems to be "hanging on" to some behaviors that most students (especially boys) outgrow by this age, such as seeking big hugs, climbing under tables or chairs while talking with adults, climbing under and over furniture, and crawling on the floor.

The IEP team has noted that Joe's speech and language goals have shifted to focus almost exclusively on pragmatic language needs. Academic concerns are not as great as concerns about his social skills, organizational skills, and use of communication for appropriate interactions. The team has most recently begun to suspect that he is displaying some features of an ASD. His parents, after reviewing literature they found online and discussing the characteristics of ASDs with the speech-language pathologist who has worked with Joe, are concerned about determining the best educational programming for Joe as he enters adolescence and have expressed this to other team members. Joe's team has begun to discuss what a free appropriate public education will look like for him as he transitions from elementary school to junior high.

To guide their decision making, the IEP team decided to conduct a formal screening for ASDs. The teacher most familiar with Joe completed the Current Version of the *Social Communication Questionnaire (SCQ)*, and the parents completed both the Current and Lifetime Versions. In many areas, the teacher and Joe's parents responded similarly. For instance, both his parents and the teacher indicated that Joe does not usually notice when others stop paying attention to what he is saying, does not engage in shared enjoyment of activities and interests with others, and does not appear to understand "turn taking" in social settings. On the SCQ Lifetime Version, the parents noted that when Joe was younger (4 to 5 years old), he did not point to items of interest or use other gestures, and he did not participate in social games like "London Bridge is Falling Down" or engage in pretend play activities. The teacher's ratings fell just at the cutoff for a positive screen, and the parents' ratings were clearly in the "at-risk" range.

The team, including the parents, decided to initiate a reevaluation to determine if Autism was a more appropriate educational disability category under which to describe Joe's needs at school and to gather information for review and revision of his IEP.

In addition to discussing the educational reevaluation, the team talked with Joe's parents about the family's possible need for and the benefits of a medical evaluation by a diagnostic clinician. The team recommended that the parents consult with Joe's PCP about this option and offered to assist by providing any relevant educational records to healthcare providers with the parents' prior written consent.

# The Referral Process

In Missouri, when screening is positive for signs of ASDs, several immediate responses should be considered, as follows:

1. A review of screening results with the parents to support their efforts to understand their child's behaviors and encourage prompt action for further evaluation. See <http://www.firstsigns.org> for guidelines about how to discuss results with a family member and for other family-oriented written materials about early development. Materials available without charge from the Centers for Disease Control and Prevention, called *Learn the Signs. Act Early*, may be especially useful in educating parents about typical developmental milestones in the social and emotional domains (<http://www.cdc.gov/ncbddd/actearly/index.html>). (See Appendices C and E for additional information.)
2. A referral to an audiologist to rule out hearing problems, as appropriate.
3. A referral to a qualified lead diagnostic clinician for a definitive evaluation (see Chapter Three).
4. A referral to state agencies and community services for individuals with developmental concerns and their families, as appropriate:
  - referral to a speech-language pathologist to initiate interventions for communication delays, if present;
  - if the child is 0–3 years old, referral to First Steps to determine eligibility for early intervention services (<https://www.mofirststeps.com/>);
  - if the child is 3 years or older, referral to the local school district to determine eligibility for childhood or other special education services;
  - regardless of age, individuals with developmental concerns can be referred to the local Regional Office service coordinators in the Division of Developmental Disabilities (see Appendix I).

Referrals to state agencies and community services must be individualized to match the specific needs of each child and family. Immediate referral may provide important supports to children and families, especially if there is a lengthy waiting period between the ASD screening and the diagnostic evaluation. For example, immediate referral to a private speech-language pathologist will support the child's development of communication skills, if this is an area of concern, and may also yield observations that are useful to the diagnostic clinician. As another example, referral to the Parents As Teachers program, which is available to all families at no charge through their local school district, can provide parents with support and activities to encourage their children's development at home.

However, it is important to note that other school programs and state agencies have eligibility criteria that each individual must meet to qualify for services (see Table 1.2 on page 17). Not all children who screen positive for ASDs will meet these eligibility criteria. For instance, children with severe developmental delays are likely to qualify for First Steps services regardless of diagnosis, but those with milder delays may not qualify unless they receive a diagnosis of an ASD first because it is a condition that automatically qualifies the child for early intervention services. Referrals made at the time of a positive ASD screening should take these factors into account. If a referral is made to a public school or to a state agency, the parent should be informed that an evaluation for service eligibility will be required and that this process is not the same as the diagnostic evaluation for ASDs. Parents should also be informed that a copy of the comprehensive clinical evaluation report is of value to schools and other service providers when making an eligibility determination for services and developing intervention plans.

## ASD SCREENING PRECAUTIONS

Not all children who screen positive will be diagnosed with ASDs. However, those who are not diagnosed with ASDs are at risk and are likely to meet criteria for another developmental disorder.

Not all children who screen positive will meet eligibility criteria for school and state agency services. If a referral is made, the parent should be aware that an evaluation for service eligibility will be required and that this process is not the same as the diagnostic evaluation for an ASD.

### BEST PRACTICE

**At-risk children and their parents are referred to intervention services and community supports based on their individual needs, even prior to completion of the ASD diagnostic evaluation.**

Other ASD referral resources for primary care providers and other front line professionals are available in Appendix E. In addition, the Office of Autism Services has developed a valuable manual, *Navigating Autism Services: A Community Guide for Missouri*, that is available online without charge at [www.dmh.mo.gov/developmentaldisabilities/officeofautismservices.aspx](http://www.dmh.mo.gov/developmentaldisabilities/officeofautismservices.aspx)

### BEST PRACTICE

**Children at-risk for ASDs and other developmental concerns are followed over time by primary care providers and other professionals in their community to ensure access to quality care.**

Another important task for the PCP or other provider of screening services is to establish a plan for follow-up with the family, whether a developmental screen is positive or negative. If the screening is negative, continued developmental surveillance in young children is essential. If it is positive, the provider can offer support to the family and help them navigate the system of care to obtain comprehensive, coordinated, community-based services.

Communicating effectively with parents about their child's developmental concerns is essential. Difficult news should be delivered with sensitivity and understanding, recognizing that this conversation can lead to earlier intervention and better outcomes for children and families. The *First Signs* website ([http://www.firstsigns.org/concerns/doc\\_parent.htm](http://www.firstsigns.org/concerns/doc_parent.htm)) describes a compassionate approach for giving feedback to families, which is summarized as follows:

- Provide adequate time and choose a place that will allow for few interruptions. Schedule another appointment if there is not adequate time the day of screening.
- Start with parent observations, questions, or concerns.
- Put yourself in the parent's shoes and be supportive.
- Focus on the need to "rule out" anything serious.
- Give parents and caregivers resources to read because some may need to come to their own conclusions about their child's development.
- Emphasize the importance of early identification and intervention.
- Be confident that sharing your concerns is always the right thing to do.

Developed for child care and other community-based service providers who work with young children, the following are ideas for talking with parents about the results of screening tests.

## TIPS FOR CONVERSATIONS WITH PARENTS FOR CHILD CARE PROVIDERS AND OTHER COMMUNITY PROFESSIONALS

- If developmental concerns are noted, begin by highlighting some of the child's strengths. Let the parent know what the child does well.
- Use materials such as the *Learn the Signs. Act Early.* fact sheets. This will help the parent know that you are basing your comments on facts and not on feelings.
- Talk about specific behaviors that you have observed in your setting. Use the milestones fact sheets as a guide. Example: If you are telling the parent, "I have noticed that Taylor does not play pretend games with the other children," you could show the parent the line on the milestones fact sheet for a 4 year old that says that a child that age "engages in fantasy play."
- Try to make it a discussion. Pause a lot, giving the parent time to think and to respond.
- Expect that if the child is the oldest in the family, the parent might not have experience to know the milestones the child should be reaching.
- Listen to and watch the parent to decide on how to proceed. Pay attention to tone of voice and body language.
- This might be the first time the parent has become aware that the child might have a developmental delay. Give the parent time to think about this and even speak with the child's other caregivers.
- Let the parent know that he or she should talk with the child's PCP soon if there are any concerns or more information is needed.
- Remind the parent that you do your job because you love and care for children and that you want to make sure that the child does his or her very best. It is also okay to say that you "may be overly concerned" but that it is best to check with the child's PCP to be sure because early action is important if the child has a developmental delay.

Adapted from the Centers for Disease Control and Prevention *Learn the Signs. Act Early.* Campaign's *Go Out and Play Kit*. Available at [http://www.cdc.gov/ncbddd/actearly/pdf/ccp\\_pdfs/GOP\\_kit.pdf](http://www.cdc.gov/ncbddd/actearly/pdf/ccp_pdfs/GOP_kit.pdf).

### BEST PRACTICE

**Information about a child's development is communicated to parents with sensitivity and understanding, noting both strengths and concerns.**

### BEST PRACTICE

**Effective communication with parents about their child's developmental progress is essential for early identification and intervention.**

# Diagnostic Evaluation

## CHAPTER 3



## Introduction

This chapter discusses diagnostic evaluation as part of an integrated process designed to promote early identification of ASDs and expedient access to a full range of appropriate community-based services. The conditions on the autism spectrum addressed in this chapter include the *DSM-IV-TR* categories of Pervasive Developmental Disorders: Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger's Disorder. These *Guidelines* emphasize that individuals with ASDs are part of larger family systems and set the stage for ongoing collaboration and communication between professionals and family members. The needs, priorities, and resources of the family are respectfully considered and used to guide each step of the process.

### **DISTINCTION BETWEEN DIAGNOSTIC EVALUATION AND ASSESSMENT FOR INTERVENTION PLANNING**

**Diagnostic evaluation** and **assessment for intervention planning** are discussed separately in this document for the purposes of clarity and detail. Although diagnostic evaluation and assessment for intervention planning may occur simultaneously, it is not essential that both steps be completed at the same time. Separate discussion of these processes facilitates application of these *Guidelines* across clinical settings regardless of whether diagnostic evaluation and assessment for intervention planning are conducted simultaneously or sequentially.

**Diagnostic evaluation** answers the question, “Is an ASD diagnosis warranted?” The purpose of the diagnostic evaluation is to collect sufficient data in the domains required by diagnostic criteria to determine whether an individual fits into a particular diagnostic category. The outcome of diagnostic evaluation is a clinical judgment regarding whether an individual meets criteria for an ASD or another developmental or psychiatric disorder.

In contrast, **assessment for intervention planning** answers the question, “What individual strengths and concerns should guide intervention planning?” Although a diagnosis (a) indicates a cluster of individual characteristics that fit in a specific category, (b) has treatment implications, and (c) is necessary for access to many services, it does not capture the diversity in expression of symptoms and levels of functioning among individuals diagnosed with ASDs. As a result, diagnosis alone typically is not sufficient for service providers to identify and individualize needed intervention services. Assessment for intervention planning builds on the diagnostic evaluation by further describing the strengths and concerns of the individual that fit within the diagnostic category. Assessment requires careful examination of the individual's functioning across multiple domains with the express objective of directing intervention planning based on the individual's unique profile of strengths and concerns. Assessment for intervention planning is discussed in detail in Chapter Four of this document.



### OVERVIEW: THE DIAGNOSTIC EVALUATION PROCESS

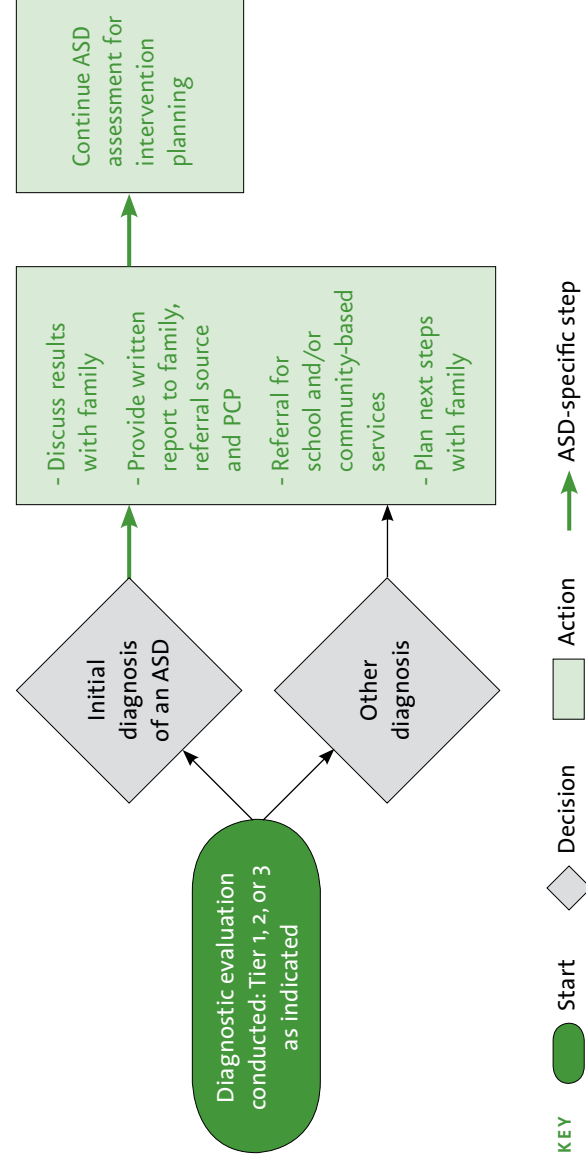
In this document, the professional responsible for conducting the comprehensive diagnostic evaluation is referred to as the lead diagnostic clinician, or lead clinician. The lead diagnostic clinician, whether acting as a sole practitioner or as part of a multidisciplinary team, has the capacity to conduct a comprehensive diagnostic evaluation based on knowledge and experience related to ASDs. The lead clinician may be the same professional who provides ongoing care or may be a consulting specialist.

The lead diagnostic clinician collects sufficient data to determine whether a diagnosis of an ASD or another disorder is warranted. Results of the comprehensive evaluation are discussed with the family and documented in a formal written report. With parental consent, the report is provided to the family, to the professional who referred the individual for diagnostic evaluation, and to the individual's primary care provider.

In all cases, regardless of whether or not an ASD diagnosis is given, the lead diagnostic clinician makes appropriate referrals for additional assessment or other services. The lead clinician collaborates with the family to determine the need for referrals to school or community-based services and to plan next steps. When an ASD diagnosis is given, the lead diagnostic clinician facilitates the transition to *assessment for intervention planning*. Figure 3.1 summarizes the diagnostic evaluation process.

### DIAGNOSTIC EVALUATION PROCESS

FIGURE 3.1



This chapter addresses the following issues related to the diagnostic evaluation process:

- essential components of diagnostic evaluation;
- interpreting diagnostic criteria within a developmental framework;
- need for further evaluation, information, and follow-up;
- special considerations for diagnostic evaluation;
- key considerations related to differential diagnosis; and
- formulating conclusions and presenting information.



## BENEFITS OF EARLY AND ACCURATE DIAGNOSIS

Clinicians may hesitate to diagnose an ASD in a young child because they are unaware of the early indicators of ASDs, are concerned about the emotional impact on the family, lack confidence in the accuracy and stability of the diagnosis, or lack knowledge of the availability of early intervention and preschool services. However, as noted in the Overview, there are a number of important benefits for the individual and the family in receiving an accurate diagnosis as soon as possible.

- The primary purpose of a diagnosis is to provide guidance for intervention. Accurate, early diagnosis leads to earlier appropriate treatment, which leads to improved quality of life and enhanced outcomes (Eikeseth et al., 2007; Howlin, 2008; Rogers & Vismara, 2008).
- Diagnostic classification often is required to access needed services through state and federally funded programs.
- Although children vary considerably within the rubric of ASDs, there are common social and communication deficits that can be recognized.
- Diagnosis provides a common language across providers and paves the way for future medical and research endeavors. This is particularly pertinent to an expanding knowledge base for ASDs. Standard diagnoses are often needed for comparison with individuals of similar profiles and are useful for tracking changes in behavior and symptom presentation over time.
- Important information is provided concerning developmental course and response to treatment.
- Most important, parents and caregivers often feel a sense of relief and comfort when they have a framework within which to understand their family member's difficulties. Similarly, diagnosis can facilitate improved self-understanding for the individual diagnosed with an ASD. However stressful it is to realize that an individual has a significant disability, knowledge is generally preferable to ambiguity.
- An early and accurate diagnosis of an ASD assists families in planning for future children.

### BEST PRACTICE

The diagnosis of an ASD is made as soon as possible to facilitate intervention and initiate family support.

## IMPORTANCE OF INFORMED CLINICAL JUDGMENT

The importance of *early* diagnosis must be balanced with the need for *accurate* diagnosis. In the absence of a single biomedical marker or simple laboratory test for identifying ASDs, early and accurate diagnosis is entirely dependent on clinical competencies. Therefore, the importance of informed clinical judgment cannot be overemphasized.

In Missouri, the lead diagnostic clinician is a professional who is licensed and qualified to render a diagnosis of ASD based upon specific training and experience. The lead clinician may be practicing independently or as part of a larger multidisciplinary team that includes one or more health or mental health professionals. Informed clinical judgment requires knowledge and experience in the areas of:

- typical and atypical development,
- the presentation of ASDs in individuals at all levels of cognitive ability from impaired to average to advanced,
- differential diagnosis of ASDs from other developmental or psychiatric disorders, and
- the presentation of ASDs across the lifespan.

### BEST PRACTICE

The lead diagnostic clinician is knowledgeable about typical child development; variability in presentation of ASD symptoms across age range, intellectual, and developmental levels; and non-autism spectrum disorders that can have symptoms similar to ASDs.

Clinicians who make an ASD diagnosis shall have at a minimum:

- Missouri state licensure as a physician, psychologist, or other health or mental health professional; and
- advanced training and clinical experience in the diagnosis and treatment of ASDs and related neurodevelopmental disorders, including knowledge about typical and atypical child development and experience with variability within the ASD population.

Rapid developments in conceptualization, measurement, and basic research on ASDs require the lead clinician to make a commitment to periodic review of new research and current best practices. This necessitates participation in ongoing education and training opportunities. The challenge in being an informed clinician is to learn about and obtain the latest screening and diagnostic instruments, stay current with new methods of evaluation and treatment, and maintain an awareness of local and regional community resources.

Because of the complexity of ASDs, it is not possible for any single clinician to maintain expertise about the full range of issues that present in every case. Therefore, the lead diagnostic clinician's self-awareness of the limits of his or her own clinical competencies is an essential aspect of informed clinical judgment. The lead diagnostic clinician is able to determine when he or she is able to make a diagnosis independently and when standardized instruments or input from other professionals are needed to inform diagnostic decision making.

### ANSWERING THE QUESTION: IS AN ASD DIAGNOSIS WARRANTED?

The experience and knowledge of the lead clinician are essential to guide the collection and interpretation of the information needed to make a diagnosis. The lead clinician collects and reviews adequate information to make or rule out an ASD diagnosis based on current *DSM-IV-TR* criteria. This professional has the ability and experience to conduct a comprehensive evaluation that includes two core elements: the individual's history and direct interaction and behavioral observation of the individual. The essential components of a diagnostic evaluation are discussed in detail later in this chapter.

Although the use of standardized instruments and input from other professionals are desirable in diagnosing ASDs, they are not essential for accurate diagnosis in all cases. Therefore, these *Guidelines* present a tiered approach to diagnostic evaluation in which the lead clinician utilizes informed clinical judgment to determine to what extent data from standardized instruments or consultation with other professionals are necessary to make or rule out an initial ASD diagnosis.

### MISSOURI'S TIERED APPROACH TO DIAGNOSTIC EVALUATION

#### Overview

Although some guidelines emphasize the need for ASD diagnostic evaluations to be completed by multidisciplinary teams, such an intensive approach is not required for accurate diagnosis in all cases and can unnecessarily delay diagnosis and expedient access to intervention, particularly when availability of specialists and specialty teams is limited. In Missouri, a tiered approach to the diagnosis of ASDs is recommended in order to provide access to diagnostic evaluation as early as possible without compromising diagnostic accuracy. The tiered approach is based on the recognition that the need for standardized measures and consultation with other professionals varies based upon the presentation of the individual being evaluated and the clinical competencies of the lead clinician.

#### INDIVIDUAL PRESENTATION

Individuals who present for an ASD diagnostic evaluation may vary considerably in a number of ways including their age and severity of symptoms. In some cases, such as a very

#### BEST PRACTICE

The lead diagnostic clinician is familiar with the psychometric properties and utility of ASD diagnostic instruments.

#### BEST PRACTICE

The lead diagnostic clinician is aware of the limits of his or her own clinical competence and utilizes standardized instruments, consultations, or referrals as necessary for accurate diagnostic decision making.

young child with behaviors that are definitively autistic in nature, the accuracy of the diagnosis resulting from informed clinical judgment of a practitioner may not be significantly increased by the results of standardized instruments or consultation with other professionals. In such cases, requiring use of specific instruments or multidisciplinary team evaluation may inadvertently delay access to intervention services.

#### USE OF STANDARDIZED INSTRUMENTS

Specialized standardized instruments are available to aid clinicians in gathering relevant information about an individual's history and evaluating the individual's presentation of specific ASD symptoms. Research indicates that the use of these instruments can improve clinical judgment both by structuring data collection and by informing diagnostic decision making, especially in cases where an individual exhibits mild or complex symptoms. However, the use of formal evaluative measures is not a replacement for clinical experience and judgment. Data obtained from standardized instruments are most valuable when they are interpreted in the context of the overall evaluation by an experienced clinician.

#### CONSULTATION WITH OTHER PROFESSIONALS

Obtaining information from other professionals based on observations or evaluations completed prior to or as part of the diagnostic evaluation can provide valuable information regarding the individual's presentation in other settings and functioning in specific domains. A single clinician's judgment can be enriched by including clinical impressions and data from other professionals who interact with or have assessed the individual. Consultation with other professionals may be most helpful in cases where an individual exhibits mild or complex symptoms or when there are specific questions that require expertise outside of the clinical competence of the lead clinician. For example, if a psychologist has questions about the extent to which a child's behaviors are impacted by seizures, consultation with a pediatric neurologist may be indicated to facilitate accurate differential diagnosis.

In Missouri's tiered approach, the lead clinician uses his or her informed clinical judgment, including awareness of the limits of his or her own clinical competence, to determine the extent to which standardized instruments or input from other professionals are needed in each individual case to make or rule out an ASD diagnosis. The lead diagnostic clinician selects the level of evaluation that best fits the needs of each individual under consideration, with higher levels incorporating increasingly sophisticated diagnostic methods and instruments. Clinicians should remain sensitive to parents' concerns regarding the completeness of the evaluation. For example, if the clinician conducts a Tier 1 evaluation and comes to a diagnostic conclusion, but the parents remain concerned and request a more comprehensive evaluation (e.g., the parents feel that the evaluation was not representative of the child's typical functioning), the clinician actively considers this request and either conducts a higher Tier evaluation or refers the child for further diagnostic evaluation.

For clarity, these *Guidelines* define three levels of evaluation that are referred to as Tier 1, Tier 2, and Tier 3. Table 3.1 provides an overview of the three levels of evaluation.

#### TIER 1

The lead diagnostic clinician determines that he or she is able to independently make a diagnosis or rule out an ASD based on clinical judgment. The clinician may choose to use standardized instruments to inform clinical judgment.

There are individuals whose ASD symptoms are severe enough and/or whose diagnosis is clear enough to an experienced clinician that a diagnosis can be rendered without the immediate need for input from other sources. In these cases, timely access to diagnostic evaluation should not be limited by guidelines that require the use of non-essential instruments or procedures.

See page 50 for a Tier 1 Case Example.

OVERVIEW OF DIAGNOSTIC EVALUATION TIERS

TABLE 3.1

	INDIVIDUAL PRESENTATION	USE OF STANDARDIZED INSTRUMENTS	CONSULTATION WITH OTHER PROFESSIONALS
<b>TIER 1</b>	Presentation of symptoms that unambiguously indicate an ASD	May be used; not required	None
<b>TIER 2</b>	Milder or more complex symptoms, difficult differential diagnosis, question about cognitive level	Yes	Possibly; consult with at least one other professional, as indicated
<b>TIER 3</b>	Very subtle or complex symptoms, some ASD symptoms with multiple co-existing concerns, complex medical or psychosocial history	Yes	Yes; consult with multiple other professionals

**TIER 2**

The lead diagnostic clinician uses data from standardized instruments and/or collaboration with *at least one* other professional, as needed, to inform his or her clinical judgment about whether an ASD diagnosis is warranted.

In some cases, the lead diagnostic clinician may determine that input from additional sources is needed to determine whether an ASD diagnosis is warranted. Particularly when an individual has a more subtle or complex presentation, the use of specialized standardized diagnostic instruments can significantly increase the clinician's accuracy and certainty. Such instruments allow the lead clinician to gather relevant information in a standardized manner and provide research-based scoring procedures that aid in decision making about the presence of an ASD. Consultation with *at least one* other professional also can aid diagnostic decision making by supplying another viewpoint or additional information based on another professional's expertise, if needed.

See page 52 for a Tier 2 Case Example.

**TIER 3**

The lead diagnostic clinician determines that the use of standardized instruments and consultation with professionals from *multiple* disciplines are needed to inform clinical judgment about whether an ASD diagnosis is warranted.

For individuals who are very complex in their presentation (e.g., have multiple coexisting symptoms, are mild in presentation, etc.), the lead clinician may work together with a team of professionals who have specific areas of expertise such as speech-language pathology, occupational therapy, medical specialties, or psychology. The team may consist of individuals within a single institution or represent the collaboration of professionals with diverse affiliations. When complex differential diagnosis is required, the lead diagnostic clinician can increase diagnostic accuracy by drawing on the diverse specialty knowledge and training of other professionals. The lead clinician retains the primary leadership role on the team and remains the primary liaison with the family.

See page 54 for a Tier 3 Case Example.

# Diagnostic Evaluation Case Examples

## CASE EXAMPLE #1: TIER 1

### DIAGNOSTIC EVALUATION BY A DEVELOPMENTAL PEDIATRICIAN

*John is a 3-year, 5-month-old boy who presents to a developmental pediatrician for comprehensive diagnostic evaluation based on a referral from his nurse practitioner due to concerns about loss of language and social skills from approximately 2½ to 3 years of age and ongoing delays in speech and language development.*

### HISTORY

**Review of Relevant Background Information.** *The lead clinician obtains the following information from a review of available educational and medical records: John has no significant medical history including no major illnesses or injuries or experiences of trauma or abuse. John does not regularly take any prescription medication. Hearing and vision have been screened at the nurse practitioner's office and found to be within normal limits. Educational records indicate that John currently receives Early Childhood Special Education Services in the Young Child with Developmental Delay Category based on delays in expressive and receptive language, adaptive functioning, and social and emotional skills.*

**Parent Interview.** *The lead clinician interviews the parents about their concerns and asks specific questions about reciprocal social interaction, communication, and repetitive behaviors and restricted interests.*

The **family's main concerns** relate to an apparent loss of skills that occurred from around 2½ to 3 years of age and ongoing delays in communication and social skills. John reportedly babbled as an infant and had a 10- to 15-word vocabulary by age 2½ years, but then stopped using most of these words until around 3 years of age. At the same time, his eye contact and level of social engagement with his parents diminished. Although John has made progress with intervention and now has a 25- to 30-word vocabulary and uses some single words to request preferred items, his expressive language remains delayed and he seems to be less socially engaged than same-age peers in his preschool.

John is an only child. There are no extended family members diagnosed with ASDs or other related disorders. He was born full-term after an uncomplicated pregnancy, labor, and delivery. Early speech and language and motor milestones occurred within normal limits until the apparent loss of skills described above.

In terms of **reciprocal social interaction**, John rarely responds when his name is called and rarely makes eye contact with others or uses gestures to communicate. He often cries and screams until his parents identify an object or action that will calm him. He is not responsive to reciprocal play such as peek-a-boo or hide-and-seek. He sometimes laughs if chased or tickled, but otherwise tends to engage in solitary activities and ignores or moves away from others if they try to engage him in play. He sometimes smiles spontaneously, but is not responsive to others' smiling at him. (CONTINUED)

(CONTINUED)

In the area of **communication**, his speech remains delayed without apparent attempts at nonverbal compensation. John does not have adequate speech to judge conversation skills. Despite his limited speech, John frequently repeats phrases he has heard on TV such as, “Use only as directed.” He does not yet demonstrate imaginative play.

With regard to **restricted interests and repetitive behaviors**, John stands on his tiptoes, flaps his hands, and sways his body back and forth when excited or agitated. He often smells or licks objects. John has an interest in electrical outlets and typically seeks out electrical outlets as soon as he enters a new environment. He insists on watching *Wheel of Fortune* and stands directly in front of the TV to watch it.

### BEHAVIORAL OBSERVATION AND INTERACTION

When greeted by the lead clinician, John did not respond verbally or nonverbally. He followed his parents and the clinician to the exam room while repeating, “Good morning, John.” When in the exam room, John began to cry and took his mother by the wrist. He led his mother toward the door without making eye contact and placed her hand on the knob in an attempt to open the door. His mother successfully redirected him by giving him a favorite dinosaur book brought from home. John sat on the floor with the book in his lap; he was largely silent, but occasionally shouted a dinosaur name. When the clinician attempted to interact with John, he did not respond to or initiate joint attention, and no sharing or showing were observed. When the clinician activated a toy that shot paper discs, John looked up and flapped his hands, but did not direct eye contact, gestures, or vocalizations toward the clinician.

### CLINICIAN’S CONCLUSION

The lead clinician determined that he had sufficient data to make a diagnosis of Autistic Disorder based on data from record review, parent interview, and direct observation and interaction without utilizing standardized instruments or consulting with another professional. John presented with a developmental trajectory and behaviors strongly indicative of an ASD that would not be accounted for by cognitive impairment alone or a speech and language disorder. The clinician discussed the diagnostic conclusions with the family and answered their questions about prognosis and next steps. The family was given the publication, *Navigating Autism Services: A Community Guide for Missouri*, from the Office of Autism Services and a few additional resources. A written diagnostic report was provided to the family and to the nurse practitioner who referred the child. The lead clinician collaborated with the family to determine the need for referrals and to facilitate the assessment for intervention planning process.



## CASE EXAMPLE #2: TIER 2

### DIAGNOSTIC EVALUATION BY A PEDIATRIC NEUROLOGIST UTILIZING DATA FROM STANDARDIZED INSTRUMENTS AND CONSULTATION WITH ANOTHER PROFESSIONAL

*John is a 3-year, 5-month-old boy who presents to a pediatric neurologist for comprehensive diagnostic evaluation based on a referral from his pediatrician due to concerns about delays in speech and language and social development.*

### HISTORY

**Review of Relevant Background Information.** *The lead clinician obtains the following information from a review of available educational and medical records:*  
John has no significant medical history including no major illnesses or injuries or experiences of trauma or abuse. John does not regularly take any prescription medication. Hearing and vision have been screened at the pediatrician's office and found to be within normal limits. John was evaluated for early intervention services at age 2½ years; although delays were documented, John's impairments were not sufficient to qualify for services.

**Parent Interview** *The lead clinician interviews the parents about their concerns and asks specific questions about reciprocal social interaction, communication, and restricted interests and repetitive behaviors.*

The **family's main concerns** relate to John's apparent delays in speech-language development. John uses primarily single-word speech and often repeats the last few words of a statement or question directed to him.

John is an only child. There are no extended family members diagnosed with ASDs or other related disorders. He was born full-term after an uncomplicated pregnancy, labor, and delivery. Early motor milestones occurred within normal limits. John did not begin using single words meaningfully until approximately 2½ years of age.

In terms of **reciprocal social interaction**, John does not respond consistently to his name, make eye contact with others, or use gestures to communicate. Within the last 2 months, he has started to point to request preferred items but does not make eye contact while doing so. He often cries and screams when others do not understand his requests until his parents identify an object or action that will calm him. He engages in some limited reciprocal play, such as playing peek-a-boo with his covers, but has only recently begun to do so. He seems to enjoy being near adults or other children but plays in a parallel manner. He smiles most of the time.

(CONTINUED)

(CONTINUED)

In the area of **communication**, his speech remains delayed with some recent attempts at nonverbal compensation. He does not yet demonstrate imaginative play.

With regard to **restricted interests and repetitive behaviors**, John tends to play repetitively with toys such as stacking or lining up objects. He flaps his hands when excited or agitated. He often smells or licks objects. John has an interest in electrical outlets and typically seeks out electrical outlets as soon as he enters a new environment. He insists on watching *Wheel of Fortune* and stands directly in front of the TV to watch it.

### BEHAVIORAL OBSERVATION AND INTERACTION

When greeted by the lead clinician, John briefly looked toward the clinician and smiled. When in the exam room, John began to cry and laid his head in his mother's lap. He calmed when given a stuffed dog from home. John inconsistently responded to his name.

### CLINICIAN'S CONCLUSION

The lead clinician determined that he did not have sufficient data to make or rule out an ASD diagnosis and would like to have data about John's developmental level and ASD symptoms from standardized instruments. The lead clinician discussed the need for additional information with the family and provided a referral to a psychologist for additional evaluation and consultation.

### RESULTS FROM THE CONSULT

Results of standardized testing indicated overall developmental delays including impaired adaptive functioning consistent with a diagnosis of Mental Retardation. Results of a standardized assessment of behaviors associated with ASDs indicated a significant level of ASD symptoms in addition to delays in social and communication skills that could not be accounted for by cognitive impairment alone. The lead clinician and consulting psychologist concluded that diagnoses of Mental Retardation and Autistic Disorder were warranted. The psychologist and the referring clinician agreed that the psychologist would discuss the results with the family and provide an integrated report including data from the pediatric neurologist's original evaluation. The psychologist discussed the diagnostic conclusions with the family and answered their questions about prognosis and next steps. The family was given a publication, *Navigating Autism Services: A Community Guide for Missouri*, from the Office of Autism Services and a few additional resources. The psychologist collaborated with the family to identify needed referrals and to continue the assessment for intervention planning process.

### CASE EXAMPLE #3: TIER 3

#### DIAGNOSTIC EVALUATION UTILIZING STANDARDIZED INSTRUMENTS AND CONSULTATION WITH MULTIPLE PROFESSIONALS

*John is a 3-year, 5-month-old boy who presents to a psychologist for comprehensive diagnostic evaluation based on a referral from his pediatrician due to a range of concerns including poor eye contact, lack of responsiveness to his name, and possible loss of language skills.*

#### HISTORY

**Review of Relevant Background Information.** *The lead clinician obtains the following information from a review of available educational and medical records:*

John has no significant medical history including no major illnesses or injuries or experiences of trauma or abuse. John does not regularly take any prescription medication. Attempts to screen hearing and vision have been limited by John's lack of cooperation. Developmental milestones for speech and language and motor development have been broadly within normal limits.

**Parent Interview.** *The lead clinician interviews the parents about their concerns and asks specific questions about reciprocal social interaction, communication, and restricted interests and repetitive behaviors.*

The **family's main concerns** relate to John's lack of social responsiveness including poor eye contact and failure to respond to his name. Since age 2½ years, John has not acquired new vocabulary words or expanded his repertoire of phrases. Recently, his parents have become concerned that he is actually using fewer words than in the past and that his speech has become more repetitive. At times he seems confused when others are speaking to him and increasingly has outbursts in response to parental requests. John has begun to hit or push his parents when he is frustrated. Sleep also is a significant concern as John often has difficulty falling asleep and tends to wake multiple times during the night.

John is an only child. There are no extended family members diagnosed with ASDs or other related disorders. He was born full-term after an uncomplicated pregnancy, labor, and delivery.

In terms of **reciprocal social interaction**, John typically does not respond when his name is called, make eye contact with others, or use gestures to communicate. He often cries and screams when others do not understand his requests until his parents identify an object or action that will calm him. He engages in some limited reciprocal play, such as playing peek-a-boo with his covers when initiated by a parent, but has only recently begun to do so. He seems to enjoy being near adults or other children but plays in a parallel manner. He smiles most of the time.

In the area of **communication**, speech remains delayed with some recent attempts at nonverbal compensation. He does not yet demonstrate imaginative play.

With regard to **restricted interests and repetitive behaviors**, John tends to play repetitively with toys such as stacking or lining up objects. He flaps his hands when excited or agitated. He mouths objects.

(CONTINUED)

(CONTINUED)

### BEHAVIORAL OBSERVATION AND INTERACTION

John did not acknowledge the clinician's greeting. He protested by screaming and crying when his parents attempted to help him transition from the waiting room to the exam room. When in the exam room, John continued to cry and laid his head in his mother's lap. He calmed when given a stuffed dog from home.

### CLINICIAN'S CONCLUSION

The lead clinician used a variety of standardized instruments to evaluate John including the *Autism Diagnostic Observation Schedule*, *Leiter International Performance Scale-Revised*, and the *Vineland Adaptive Behavior Scales, Second Edition*.

The lead clinician discussed her initial clinical impressions with John's family and explained the need for additional consultation prior to formulating final diagnostic conclusions. The psychologist encouraged the family to contact their local school district regarding John's eligibility for Early Childhood Special Education Services and indicated that the final evaluation report could be shared with the school upon its completion. Consultation with a speech-language pathologist was arranged to determine John's profile of language skills because of parental concerns about possible loss of both receptive and expressive language. In addition, consultation was arranged with a pediatric neurologist to rule out the possibility of a seizure or other neurological disorder, such as Landau-Kleffner Syndrome, that might account for John's presentation of apparently normal development followed by loss of language skills in combination with aggression and sleep problems.

### RESULTS FROM THE CONSULT

Results of standardized testing indicated nonverbal cognitive ability in the borderline to low average range combined with impaired adaptive functioning. John's scores on the ADOS were above the cut-off scores for Autistic Disorder. Speech and language evaluation indicated delays in receptive and expressive language; when motivated by access to preferred items, John was able to demonstrate a higher level of skills than he initially presented. Results of a sleep EEG completed as part of a neurological evaluation were unremarkable. The pediatric neurologist reported that there was no evidence of Landau-Kleffner syndrome or other specific neurological disorders. Based on a review of the results of her initial evaluation and information from consulting professionals, the psychologist concluded that a diagnosis of Autistic Disorder was warranted. The psychologist discussed the diagnostic conclusions with the family and answered their questions about prognosis and next steps. The family was given a written evaluation report along with a publication, *Navigating Autism Services: A Community Guide for Missouri*, from the Office of Autism Services and a few additional resources. The psychologist collaborated with the family to identify needed referrals and to begin the assessment for intervention planning process. The consulting pediatric neurologist agreed to follow up with the family regarding John's sleep problems and to provide comprehensive medical evaluation to inform assessment for intervention planning. The speech-language pathologist also agreed to follow up with the family. The psychologist's written evaluation report was forwarded to John's local school district for consideration in the special education eligibility determination process.

# Essential Components of Diagnostic Evaluation

## OVERVIEW

During the diagnostic evaluation, the lead clinician collects sufficient data in the domains required by diagnostic criteria to determine whether a diagnosis of ASD or another neurodevelopmental or psychiatric disorder is warranted. Although additional assessment is needed for intervention planning, completion of components not essential to diagnosis should not delay the initial diagnostic evaluation. Therefore, this document distinguishes between *diagnostic evaluation* and *assessment for intervention planning* and identifies the components that are essential for diagnosis in order to increase access to services and timeliness of initial diagnosis.

Autism spectrum disorders (ASDs) are defined behaviorally with respect to three key areas of functioning: (a) reciprocal social interaction, (b) communication, and (c) restricted interests and repetitive behaviors. The diagnostic evaluation process requires thorough examination of these components as well as their relationships with family functioning and medical and health history. The diagnostic evaluation for ASD necessarily considers data from multiple sources about the individual's functioning across multiple domains. All comprehensive diagnostic evaluations, regardless of the tier at which they are conducted, include a *minimum* of two components:

1. a thorough history based on obtaining and reviewing available records and a parent/caregiver interview, *and*
2. direct interaction and behavioral observation of the individual engaged in tasks that allow sufficient opportunity to gauge his or her behavioral presentation (e.g., play, social interaction, etc.).

Although practices vary somewhat across clinical settings, a comprehensive diagnostic evaluation including the core components listed in Table 3.2 might progress as follows:

1. Review relevant records.
2. Interview parents/caregivers and individual (as appropriate).
3. Observe and interact with the individual.
4. Evaluate using standardized instruments (if indicated).
5. Consider alternative diagnoses.
6. Make a diagnostic determination.
7. Communicate findings and next steps to the family.

### BEST PRACTICE

The lead diagnostic clinician has the knowledge, experience, and clinical judgment to conduct comprehensive evaluations that include two core elements: the individual's history, and direct interaction and observation of the individual.

### BEST PRACTICE

The lead diagnostic clinician allots adequate time and materials to complete a review of relevant records, a thorough parent interview, and direct interaction and behavioral observation of the individual.

### BEST PRACTICE

Face-to-face behavioral observation and interaction are essential components of diagnostic evaluation.

ESSENTIAL COMPONENTS OF DIAGNOSTIC EVALUATION

TABLE 3.2

<p><b>HISTORY</b></p> <p><b>Obtain and Review Available Records</b></p> <p><b>Parent/Caregiver Interview</b></p>	<ul style="list-style-type: none"> <li>▪ Results of any developmental and/or ASD screening completed</li> <li>▪ Relevant records may include:                         <ul style="list-style-type: none"> <li>– medical records</li> <li>– prior developmental or behavioral evaluation reports</li> <li>– intervention records</li> <li>– school records</li> <li>– parent records of early development</li> </ul> </li> <li>▪ Additional information from parents, teachers, and others familiar with the child such as standardized behavioral rating scales</li> <li>▪ Developmental and behavioral history and current functioning of the child with particular attention to diagnostic criteria for ASD including milestones, delays, and any concerns about regression; development of social, communication, and play skills; and presence of any repetitive behaviors or unusual interests</li> <li>▪ Family social, medical, and mental health history</li> </ul>
<p><b>BEHAVIORAL OBSERVATION AND INTERACTION</b></p>	<p>During face-to-face interaction, the clinician observes behaviors relevant to ASD diagnostic criteria and differential diagnosis such as:</p> <ul style="list-style-type: none"> <li>▪ Reciprocal social interaction                         <ul style="list-style-type: none"> <li>– social approach and response</li> <li>– sharing interests or enjoyment</li> <li>– joint attention</li> <li>– response to name</li> </ul> </li> <li>▪ Communication                         <ul style="list-style-type: none"> <li>– quality, quantity, content, and use of verbalizations</li> <li>– use of nonverbal communication to compensate for delays in spoken language</li> <li>– play skills including imitation and imagination</li> </ul> </li> <li>▪ Restricted interests and repetitive behaviors                         <ul style="list-style-type: none"> <li>– use of toys and objects</li> <li>– any problem behaviors</li> <li>– any preoccupations</li> <li>– repetitive behaviors</li> </ul> </li> </ul>

## HISTORY

A comprehensive history includes a review of relevant background information and a parent/caregiver interview that addresses the individual's past and present functioning.

### Review of Relevant Background Information

The lead diagnostic clinician is responsible for determining what background information is needed to aid differential diagnosis or inform the diagnostic evaluation process. An attempt should be made to obtain all relevant records. Background information is reviewed and integrated to guide the focus of the evaluation. Relevant records may include:

- results of any developmental or ASD screening that has been completed or the nature of the referring provider's concerns;
- behavioral reports and additional observations from parents and others familiar with the individual;
- medical records such as birth records, results of newborn screening, medication history, history of prior medical diagnoses, any inpatient records, and results of any previously completed medical testing;
- results of prior evaluations such as speech and language skills, occupational or physical therapy, school-based testing, psychological or neuropsychological evaluations, or functional behavioral assessment;
- early intervention records (e.g., First Steps or Early Childhood Special Education);
- school records (e.g., Evaluation Summary Report, Individualized Education Program [IEP], and Progress Reports);
- parent records of early development (e.g., videos or notes); and/or
- evidence or parent report of physical or sexual abuse or other traumatic experiences.

The lead clinician reviews relevant background information for data about the individual's developmental course and behaviors. Any prior evaluations are reviewed to determine how previous evaluators reached their diagnostic conclusions. Collateral information from parents and others familiar with the individual (e.g., child care provider or teachers), including completion of standardized behavior rating scales, is reviewed to examine the individual's reported behavior across settings.

The amount of prior information often is dependent on the age of the child, with younger children typically having had fewer encounters with professionals. An extensive set of records from the first years of life is more likely to follow children who have significant impairments (e.g., motor, sensory, etc.), including those with risk factors for a developmental disability (e.g., premature birth, birth complications, substance exposure). Older children may have school, psychological, or speech and language reports.

Procedures for obtaining relevant background information vary among clinicians and institutions so that information may be obtained prior to, at the time of, or subsequent to the clinician's initial meeting with the family. In order to maximize efficiency, it often is helpful for the lead clinician to make attempts to obtain records (with the parents' consent) prior to the parent interview.

Parents can facilitate clinician access to information by maintaining a file of documents relevant to their child's development to eliminate the turnaround time required to obtain records from third parties. When background information is available prior to the evaluation, it can be used to guide discussion with parents as well as to guide interaction and observation of the child. Collection of demographic data and basic background information prior to the parent interview allows time allotted for direct clinician-parent interaction to be focused specifically on parent concerns and questions as well as for detailed discussion of the individual's past and present functioning in the areas specific to an ASD

#### BEST PRACTICE

Completion of standardized behavior ratings or other data collection procedures by professionals in multiple settings provides valuable information about the individual's functioning.



diagnosis (i.e., reciprocal social interaction, social communication, and restricted interests and repetitive behaviors).

## Parent/Caregiver Interview

### OVERVIEW

Parents are experts on their particular child and, as a result, are an essential source of information about their child regardless of the child's age (Goldstein, Ozonoff, Clark, & Cook, 2009). The lead diagnostic clinician must possess exceptional skills in interviewing and regard parents and caregivers with the respect they deserve as essential partners in the diagnostic process.

Although background information may be obtained prior to the family's initial appointment, the parent interview often represents the family's first face-to-face interaction with the lead clinician. Parents and caregivers should feel comfortable and relaxed during the interview and confident providing information. At the beginning of the visit, the lead diagnostic clinician works to reduce anxiety and uncertainty about the evaluation process by introducing himself or herself to the family and providing the family with an overview of the evaluation process. The clinician explains his or her role and the schedule of activities for the day. Explanations are provided for all evaluation procedures and parent interview questions. The clinician ascertains that informed consent for evaluation has been obtained and addresses any initial questions or concerns from the family. Assuring parents or caregivers that a comprehensive evaluation will be conducted inspires greater confidence in the resulting diagnostic conclusions and recommendations.

Semi-structured or structured interview measures may be used to guide the interview and are discussed in more detail below. Regardless of the selected format, parent questions and concerns should be identified at the outset and provide the focus for the interview. Before asking about specific behaviors, the lead diagnostic clinician elicits parent concerns through open-ended questioning. For example, the clinician may ask the parents about their main concerns or what questions they hope to have answered at the end of the evaluation.

Although parents have the utmost knowledge of their child, they also often have the highest degree of adaptation to their child's nature of communication and behavior. Compensation for subtle or more pronounced child deficits may not be apparent (Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1999). Further, some parents may reframe concerns in terms of their own experiences or that of relatives or friends (e.g., "I wasn't popular at school either."). Therefore, the lead clinician must be able to interpret information obtained in the parent interview in the context of such factors and overall evaluation data.

### CONTENT OF THE PARENT/CAREGIVER INTERVIEW

The Parent/Caregiver Interview thoroughly explores parental concerns and elicits detailed information about the developmental history and past and present behaviors of the individual being evaluated. The lead clinician asks questions and interprets responses within the framework of typical development and knowledge of individual family characteristics. When asking parents to recall the timing of specific behaviors, it may be helpful to provide a reference point (e.g., first birthday, where family lived, other significant events at that time) to aid with recall. In addition, probing specific events like a birthday or holiday celebration can be more helpful in eliciting detail than a broad question that demands a caregiver's reflection on years of memories (Klin, Sparrow, Marans, Carter, & Volkmar, 2000).

The clinical content of the parent interview should document the individual's overall development; reciprocal social interaction skills; communication skills; any restricted interests or repetitive behaviors; and the family's social, medical, and mental health history.

#### BEST PRACTICE

**The lead diagnostic clinician builds a partnership with parents and caregivers throughout the diagnostic evaluation process. This partnership begins by respecting parents' expertise about their child and focusing on parent questions and concerns.**

**Overall development.** The lead clinician interviews the parents or caregivers about their child's previous development and current functioning. The clinician determines if the individual's pattern of development is consistent with an ASD diagnosis and considers the individual's behaviors in the context of his or her overall development. Relevant developmental information typically is obtained by interviewing the parent or caregiver about areas such as:

- initial concerns including the age of the child when parents or others first became concerned about the child's development, the nature of the concerns, and initial interpretation of these concerns;
- developmental milestones for early speech and language development and motor skills;
- developmental regression including any skill loss or behavioral deterioration; and
- adaptive skills and current level of functional independence.

**Reciprocal social interaction.** The parent/caregiver interview includes specific questions related to reciprocal social interaction as described by diagnostic criteria for ASDs. The lead clinician obtains a description of the individual's *past and present* functioning in areas such as:

- patterns of attachment to caregivers;
- engagement in reciprocal social games (e.g., peek-a-boo) or exchanges (e.g., conversation);
- social use of nonverbal behaviors such as eye contact, facial expressions, and gestures;
- emotional reciprocity such as shared enjoyment and empathy;
- social approach and response; and
- interest in peers and/or siblings.

**Communication.** The parent/caregiver interview includes specific questions related to communication as described by diagnostic criteria for ASDs. The lead diagnostic clinician obtains a description of the individual's *past and present* functioning in areas such as:

- use of language including communicative intent,
- any stereotyped or idiosyncratic use of words or phrases,
- use of nonverbal communication to compensate for delays in spoken language, and
- play skills including pretend and interactive play.

**Restricted interests and repetitive behaviors.** The parent/caregiver interview includes specific questions related to restricted interests and repetitive behaviors as described by diagnostic criteria for ASDs. Parent/caregiver report in this domain is particularly important because restricted interests and repetitive behaviors may not be demonstrated during brief clinical observations. The lead diagnostic clinician obtains a description of the individual's *past and present* behaviors such as:

- motor stereotypies,
- unusual sensory interests or aversions,
- atypical or narrow interests and activities, and
- compulsion or rituals.

**Family social, medical, and mental health history.** The focus of this portion of the interview is to identify any psychosocial factors or medical, developmental, or psychiatric disorders in the family history that may assist in differential diagnosis. Current research clearly indicates a genetic component associated with ASDs, in addition to related developmental disabilities (e.g., cognitive impairment), lesser variants (e.g., language disorder, learning disability), and phenotypic traits (e.g., schizotypal). A strong psychiatric history within a family (i.e., schizophrenia or a mood disorder) may indicate a different diagnostic trajectory outside the autism spectrum that may be difficult to differentiate in a young child. However, it

should be noted that there is also a moderate increased risk of co-occurrence of mood disorders and anxiety disorders in family members of persons with ASDs (Piven & Palmer, 1999).

Parents and caregivers should be well informed regarding why such information is necessary for diagnostic clarity and treatment planning as well as implications for future family planning. Given that a medical or psychiatric history is often a sensitive topic, particularly for parents of children suspected of having ASDs, the clinician should be attuned to discomfort and be able to discuss the clinical necessity and implications of the findings. With regard to confidentiality, information should be shared only with providers who have clinical use for the information with parent consent.

#### USE OF STANDARDIZED INTERVIEW INSTRUMENTS

The parent interview can be either a standardized interview or a more informal gathering of information. Clinicians experienced in the diagnosis of ASDs tend to rely more on informal interview questions that are specific to the diagnostic criteria for ASDs and are relevant to the child's age and developmental level. Standardized interviews, such as the *Autism Diagnostic Interview, Revised* (ADI-R; Lord, Rutter, & LeCouteur, 1994), are semi-structured and, although constrained by administration protocol in gathering information, provide very complete developmental and behavioral information. It is important that such instruments be used by a skilled clinician so that the formalities and protocols do not provoke undue anxiety for parents who are likely already apprehensive about their child. Informal procedures used alone or in conjunction with formal instruments often allow the clinician more flexibility in providing examples of specific behaviors for the parents. An informal approach allows for reframing the wording of questions to increase comprehension.

The results of formal questionnaires and interview instruments can be used as a guide but must be interpreted with regard to their reliability and validity in diagnostic accuracy with respect to the age and characteristics of the individual being evaluated. The interview data gathered should be specific to the age of the individual and interpreted within the context of typical development. For example, the *Childhood Autism Rating Scale* (CARS; Schopler, Reichler, DeVellis, & Daly, 1980), a popular interview instrument, tends to be overly inclusive for very young children who are cognitively impaired and not inclusive enough for those who do not have clear restricted interests or repetitive behaviors. Thus, it is important for the clinician to be well versed in the developmental manifestations of the disorder at different ages to be able to frame useful and diagnostically relevant questions. A listing of instruments that may be used to gather background information and interview data is provided in Appendix F.

#### BEHAVIORAL OBSERVATION AND INTERACTION

Direct observation of the individual's behavior and interaction with the individual are essential to a diagnostic evaluation for several reasons (Goldstein et al., 2009). Direct observation allows the lead diagnostic clinician to use his or her expertise to evaluate the individual's behavior in structured and unstructured situations. Although parents may have difficulty interpreting items on questionnaires or recalling information to answer interview questions, direct observation allows the clinician to structure situations to observe specific behaviors and ascertain whether these behaviors are typical. Observation can help to identify deficits that parents may not report because of their unknowing compensation (e.g., parents who report adequate eye contact because they physically position themselves in a manner that prompts eye contact). Finally, observations allow the clinician to observe patterns of interaction with family and unfamiliar adults. When siblings are able to attend the diagnostic evaluation, it may be helpful to observe sibling interactions, as well. This is not essential but should be accommodated if appropriate.

Diagnostic criteria for ASDs include both positive and negative symptoms. Positive symptoms are readily observable behaviors such as echolalia or motor stereotypies and typically are the easiest to document. Negative symptoms are more difficult to evaluate because they refer to the absence of typical behaviors such as a lack of social reciprocity or lack of imaginative play. The lead clinician, through the use of formal instruments (e.g., Autism Diagnostic Observation Schedule [ADOS]; Lord, Rutter, DiLavore, & Risi, 1999) or otherwise, creates situations and allows sufficient time to document behavioral deficits in the domains required for an ASD diagnosis.

### **Structuring the Environment for Behavioral Observation and Interaction**

#### **MATERIALS**

Selection of materials is based on consideration of the individual's chronological age, gender, and developmental level. Materials provided include items that typically are appealing to other individuals of the same age and gender, as well as items typically used by younger and older individuals. For example, providing a school-age child with access to infant toys allows an opportunity to observe repetitive use of objects or unusual sensory interests or aversions. Information obtained from reviewing relevant records and interviewing the parent or caregiver can help guide in material selection so that individuals are neither overwhelmed nor underchallenged. Gearing toys or other materials as closely as possible to the individual's level of functioning and interests will lead to a greater likelihood of observing typical behaviors for the individual. It also can be beneficial to intentionally select toys or other materials that tend to elicit behaviors associated with ASDs. For example, a doll with moveable eyes or a puzzle with moveable parts may elicit repetitive manipulation, visual inspection, or other unusual sensory behaviors.

#### **DEGREE OF STRUCTURE**

The lead clinician observes and interacts with the child in structured and unstructured situations. Structured observations allow the clinician to press for specific behaviors common to individuals with ASDs. Structured observations may be limited by noncompliance and elicit atypical behaviors because of unfamiliarity with materials and difficulty with changes in activity and interactive partners. In such instances, the lead clinician interprets the individual's difficulties with structured activities, novelty, and/or transitions in the context of typical development and overall evaluation data to determine the clinical significance of these behaviors.

Unstructured observations of child behavior often provide the clinician with a more representative sample of the child's typical behaviors and use of play materials in the absence of specific adult demands or intrusions. For the purposes of establishing functioning levels, unstructured observations provide information regarding behavior that is typically displayed rather than that which is evidenced in response to specific environmental influences. Unstructured observations may take place in a range of settings, including in the clinic waiting room, while the clinician is greeting the family, while walking to the evaluation room, or during snack or bathroom breaks.

#### **LOCATION**

The space available for the evaluation allows ample room for comfortably talking with the family and observing and interacting with the child. The room should be "child friendly" with a variety of toys that correspond to various developmental levels available to the child or other materials appropriate to the developmental level of the individual being evaluated. Medical exam rooms that are small and lacking in materials generally inhibit children and severely limit behavioral expression. The room should be large enough to allow the child to play away from the adults.

### Domains to be Evaluated Through Direct Observation and Interaction

The lead diagnostic clinician structures the environment and allows ample time to observe and interact with the child to document relevant behaviors, including behaviors in the domains of *reciprocal social interaction*, *communication*, and *restricted interests and repetitive behaviors*. Table 3.3 lists behaviors that can be observed in each of these domains.

DOMAINS TO BE EVALUATED THROUGH DIRECT OBSERVATION AND INTERACTION		
RECIPROCAL SOCIAL INTERACTION	COMMUNICATION	RESTRICTED INTERESTS AND REPETITIVE BEHAVIORS
<ul style="list-style-type: none"> <li>▪ Social approach and response</li> <li>▪ Quality of social interaction</li> <li>▪ Shared enjoyment</li> <li>▪ Joint attention</li> </ul>	<ul style="list-style-type: none"> <li>▪ Quality, quantity, content, and use of verbalizations</li> <li>▪ Play skills including imitation and imagination</li> <li>▪ Use of nonverbal communication to compensate for delays in spoken language</li> </ul>	<ul style="list-style-type: none"> <li>▪ Use of toys and objects to determine if their use is functional, imaginative, repetitive, or otherwise atypical</li> <li>▪ Any problem behaviors such as aggression, agitation, distractibility, or compulsive behaviors</li> <li>▪ Any preoccupations, repetitive behaviors, motor stereotypies, or sensory preferences</li> </ul>

Even when adequate time for observation and interaction is allotted, motor stereotypies or other repetitive behaviors or unusual interests may not be observed in the course of a single evaluation. Therefore, behavioral reports from parents and other collateral informants are essential in documenting the presence of behaviors in this area.

In addition, when permitted by the individual's developmental level and language skills, direct behavioral observation includes an interview with the individual to gain information about relevant diagnostic domains such as emotional reciprocity and peer relationships.

This list of behaviors in Table 3.3 is not exhaustive but is intended to describe a sampling of behaviors supporting and associated with diagnostic criteria for ASDs. It is critical that all behavior be interpreted within the context of the age and developmental level of the individual, as well as the individual's level of engagement and cooperation during the evaluation. Through discussion with the parent or caregiver and consulting collateral information, the lead diagnostic clinician determines the extent to which the individual's observed behaviors are consistent with his or her behavior in other settings.

### Use of Formal Observation Instruments

The use of a formal observation measure based on psychometric data allows for more standardized documentation of symptoms and behaviors. Research also indicates that use of a standardized behavioral observation instrument (e.g., *ADOS*) increases diagnostic accuracy. When the lead diagnostic clinician determines that use of a standardized observation instrument is clinically indicated, a diagnostic instrument "with at least moderate sensitivity and good specificity for autism" is selected (Filipek et al., 2000, p. 475). More detailed information about formal observation instruments is provided in Appendix F.

## Interpreting Diagnostic Criteria Within a Developmental Framework

The lead clinician interprets evaluation data in the context of typical development and the individual's developmental level. The *DSM-IV-TR* indicates that “the qualitative impairments that define these conditions [Pervasive Developmental Disorders] are distinctly deviant relative to the individual's developmental level or mental age” (APA, 2000, p. 69).

The lead clinician discriminates atypical behaviors from typical developmental patterns. For example, many preverbal children flap their arms and jump when excited or frustrated. In order to determine whether such repetitive motor mannerisms are atypical, the clinician considers these behaviors in the context of typical development and the individual's developmental level.

Information about the individual's developmental level may be evaluated based on data collected via parent interview and direct behavioral observation regarding the child's progression and current functioning in the major domains of development (i.e., motor, speech and language, and self-help). Such informal evaluation of developmental level and adaptive functioning may be indicated in very young children (i.e., children under age 3 years) or when the individual's behavior precludes valid administration of standardized measures. Results of standardized developmental and adaptive measures are not essential for diagnosis when a clinician with expertise in the area of ASD documents atypical behaviors strongly indicative of an ASD in addition to delays in communication and social skills.

Although administration of standardized developmental and adaptive measures is not essential for a diagnosis of an ASD in all cases, such test results may increase diagnostic accuracy and confidence and may be required in order to document eligibility for state- or school-based services. Therefore, when appropriate, standardized instruments are administered to assess the child's level of development or cognitive ability and current adaptive functioning as part of the diagnostic evaluation process. If standardized instruments are not used to assess developmental level or cognitive ability and adaptive behavior prior to or during the initial *diagnostic evaluation*, the lead diagnostic clinician provides a referral to a qualified professional who can complete cognitive and adaptive testing as part of the *assessment for intervention planning* process.

## Need for Further Evaluation, Information, and Follow-Up

In some cases, a definitive diagnostic presentation is not readily apparent. This may be true for a young child or an individual with severe or very subtle impairments. At no time should the lead diagnostic clinician diagnose a child without confidence in that clinical conclusion. The clinician should be prepared to discuss with parents the reasons underlying ambiguity and the provisions for clarification.

In cases of clinical uncertainty, the lead diagnostic clinician formulates a plan of action for gaining further information. If a Tier 1 evaluation has been completed and the lead diagnostic clinician remains unsure of the diagnosis, he or she may move to a Tier 2 evaluation by utilizing standardized instruments or consulting with at least one other professional. If the lead diagnostic clinician who conducted the initial Tier 1 evaluation is not able to complete a Tier 2 evaluation, he or she refers the family to another clinician who can serve as the lead diagnostic clinician for a Tier 2 evaluation. Similarly, if a lead diagnostic clinician has completed a Tier 2 evaluation that results in diagnostic uncertainty, he or she takes steps to initiate a Tier 3 evaluation or refers the family to another clinician who can do so. Tier 3 evaluations that utilize both standardized instruments and input from multiple professionals specifically are indicated in complex cases when prior evaluations have not resulted in a firm diagnosis. It is possible that a Tier 3 evaluation also may result in diagnostic uncertainty. In such instances, it may be helpful to use terms such as “baseline” or “provisional” in conjunction with a diagnosis. Referrals for relevant interventions and assessment for intervention planning are made along with specific plans for progress monitoring and follow-up evaluation.

Similarly, as discussed earlier in this chapter, clinicians should be sensitive to the parents’ concerns regarding the completeness of the evaluation. If parents feel as though the evaluation is not representative of the child’s functioning, the clinician should consider this input and either conduct a higher Tier evaluation or refer the individual for further diagnostic evaluation.



## Special Considerations for Diagnostic Evaluation

The lead diagnostic clinician is knowledgeable about the variability in presentation of ASD symptoms that can occur based on the individual's gender, age, or developmental level. When selecting diagnostic procedures and formulating conclusions, the individual's specific presentation is taken into consideration.

### DIAGNOSING ASDs IN YOUNG GIRLS AND YOUNG WOMEN

Females with ASDs tend to be identified later than males (Shattuck et al., 2009) despite the fact that females with ASDs often exhibit a greater degree of cognitive impairment than males and that, in general, children with more severe impairment have been found to be identified as having ASDs at younger ages (Mandell, Novak, & Zubritsky, 2005). Increasing clinical and research evidence supports the idea that this delayed diagnosis of females with ASDs may be due to differences in their symptom presentation when compared to males with ASDs. For example, McLennan, Lord, and Schopler (1993) found that boys with ASDs may exhibit more social and communication impairments in early childhood, whereas girls' social difficulties may become more apparent in adolescence. Nichols, Moravcik, and Tetenbaum (2009) noted that females with ASDs also have been found to differ from males with ASDs in terms of lower IQ scores, fewer restrictive and repetitive behaviors, better imaginative play, better attention and concentration, and lower parent ratings of social skills that may reflect higher social expectations for girls.

Because of the higher prevalence of ASDs in males, diagnostic criteria and instruments tend to reflect the presentation of ASDs in males and may not account for possible variations in symptom presentation based on gender. Therefore, when a diagnostic evaluation is conducted to determine whether an ASD diagnosis is warranted for an individual who is female, the lead clinician considers the individual's presentation in comparison to other females of the same age and cognitive ability and uses clinical judgment in evaluating scores from diagnostic instruments that fall just below diagnostic cut-offs (Koenig & Tsatsanis, 2005).

### DIAGNOSIS OF VERY YOUNG CHILDREN

Clinical judgment must supersede and inform data gained by instruments, observations, and interviews, particularly for children younger than 3. For example, it has been demonstrated that young children under 3 years of age who are diagnosed with ASDs often do not meet all formal diagnostic criteria at age 2 (Lord, 1995; Zwaigenbaum et al., 2009). Specifically, these children often do not display clear repetitive interests or stereotypic motor movements. At age 2, these children often demonstrate more impairment in social-communicative and joint attention behaviors. In essence, the clinician should be highly cognizant of the limitations of formal diagnostic criteria in young children and familiar with research regarding their developmental expression. The only interview format instrument with adequate psychometric properties for children under the age of 5 years is the *Autism Diagnostic Interview-Revised* (ADI-R; Lord, Rutter, & LeCouteur, 1994).

In very young children, behavioral observation should include the child's interactions with both the clinician and the parent/caregiver.

The lead clinician makes recommendations regarding the need for re-evaluation of preschool-aged children on a case-by-case basis. Although clinicians with expertise in ASDs have the capacity to make a definitive ASD diagnosis, presentation of ASD symptoms may fluctuate in preschool-aged children particularly if an initial diagnosis is made at age 2 years or younger or if initial symptoms are described as very severe or very mild. Subsequent to intervention, it is not uncommon for a child who was diagnosed with Autistic Disorder at 2 or 3 years of age to be described as PDD-NOS at age 4 or 5 years. At the same time, certain ASD symptoms such as circumscribed interests and lack of peer relationships may become more pronounced at age 4 or 5 years, so that a child described as PDD-NOS at age 3 years may receive a diagnosis of Autistic Disorder at age 4 or 5 years.

### DIAGNOSTIC EVALUATION FOR INDIVIDUALS AGE 6 YEARS AND OLDER

Diagnosing older children or individuals may differ from evaluation of young children in a number of important ways:

- Differential diagnosis can be more challenging because of the increasing possibilities for alternative diagnoses and the long-term effects of environmental interactions on behavior. The clinician must be familiar with ASDs, as well as the range of psychiatric, neurodevelopmental, and behavioral disorders that are either primary or coexisting conditions. Although little is known about the developmental expression of major psychiatric disorders in very young children, the clinical picture becomes more differentiated as children mature.
- Asperger's Disorder will emerge more frequently as a potential diagnosis because the features of this disorder are generally more salient or more apparent in contrast to same-age peers as the child gets older.
- Establishing an early developmental history is more challenging as the age of the individual increases. As a result, records and multiple sources of data become more important.
- The clinician may have opportunities for direct interview of a child with adequate language skills in addition to observation and interviewing the parents or caregivers. Thus, the clinical team should have experience conducting assessments, forming relationships, and interviewing children in this age group.
- Collaboration with service providers, schools, and other healthcare entities will often be a necessary component of the diagnostic process.

#### Record Review – 6 Years and Older

When a child is older at the time of first presentation for diagnostic evaluation, there will likely be more information for review. Sources of information may include previous medical, school, and psychological records. Data from other evaluations or intervention reports (e.g., behavioral, speech) are also valuable sources of information. The child will also have had more contact with the community outside the family (e.g., school, neighborhood), which provides the opportunity for more collateral information.

To a larger degree than when working with younger children, the clinician must juxtapose descriptions of current behaviors with those previously reported to corroborate those behaviors or define new ones. This information aids in planning the evaluation and is helpful in differential diagnosis. In addition, a review of the records will direct the clinician's approach to evaluation as well as establish developmental trends and identify salient avenues of investigation during observations and interviews. The developmental course of ASDs varies considerably with respect to child and environmental factors.

Previous records can supplement and assist parent recall. For example, although a parent may not remember whether a child began talking at a developmentally appropriate age, medical and school records may indicate that speech and language services were provided. When there are other children in the family, developmental milestones may begin to “merge” as children get older. Current videotapes and those of early childhood can be helpful for review.

Previous records also allow clinicians to review issues of concern to the family as well as descriptions of behavior that may have led clinicians to earlier conclusions. The focus of record review is more to examine past descriptions of behavior rather than to reach diagnostic conclusions. Finally, the review of records and clarification of definitions in the parental narrative can lead to a more concise conceptualization of the current concerns.

### **Parent/Caregiver Interview – 6 Years and Older**

Initially, the clinician should clarify the nature of the evaluation and its consistency with parental expectations. Many times, older children present for evaluation because of conflict with service providers as to the nature of the child’s difficulties and the most appropriate course of intervention.

Interviews of parents of older children pose additional challenges to the clinician. The tremendous range of syndrome expression in general and the mild and atypical nature of symptoms of “higher functioning” individuals in particular are further complicated by the fact that the older the individual, the more difficult it may be for family members and other caregivers to recall specifics about developmental milestones and other aspects of early childhood. Similarly, parents of children with significant cognitive impairment are often not aware of or unclear about the extent of their child’s disability and expectations for remediation. Earlier history may be described and interpreted in light of current challenges. It is not unusual for parents and caregivers to suspect their child has an ASD because of either a suggestion by the referring party or a recent diagnosis from someone less familiar with the disorders. In these instances, current information can influence recall. One method for increasing reliability of parent report is the presence of both parents and/or another significant caregiver, such as a teacher or close family friend. It is also helpful to frame questions within descriptions of current events. This may entail having the parent describe a familiar routine and/or activity.

### **Direct Observation and Interaction – 6 Years and Older**

With verbal children and adolescents, information may be gathered through direct interview. The specific format can be either formal or informal and is dependent upon the specific referral questions. Before discussing the content of the interview, several factors should be assessed regarding the communication skills and style of the verbally fluent individual. These factors are particularly enlightening regarding differential diagnosis and exploration of pragmatic deficits. They include:

- the ability to manage conversational interchange—topic management, initiation, response ratios, shifting, maintenance, and extension;
- the ability to recognize and respond to clarification or requests or to request clarification;
- the ability to interpret non-literal language accurately such as humor, sarcasm, irony, etc.;
- the ability to recognize indirect and polite forms;
- the awareness of a need for shifts in register—i.e., teacher/student, peer/peer (this may be observed in other contexts);
- the capacity to modulate tone and volume and other prosodic features;
- the flexibility to deal with a range of situations and the ability to modulate responses; and
- nonverbal communication, which includes shifts in eye gaze, body positioning, etc.

These factors are often helpful in establishing differential diagnostic features of communication style, regardless of language content. For example, with minimal prompting, persons with Asperger's Disorder are eager to discuss their area of interest. They are also not usually prone to allow the interviewer to expand or add information or share his or her own interests. The taping of interviews is often helpful in that features can be reviewed in more detail later and/or with parents when appropriate. It is extremely important to retain the utmost respect for the child's (more typically the adolescent's) wishes for confidentiality of shared information and comfort with taping and observation.

Interviews with children of this age can take many forms and are dependent on the referral question, the child's ability level, and the interviewer's own experience. Clinical expertise in interviewing children is crucial. This includes an understanding of the response style of children at various ages and developmental levels, children with ASDs, and children with non-autistic disorders. Regardless of the referral question or diagnostic considerations, children presenting for an evaluation are not without some significant concern regarding behavior, development, and/or social emotional functioning. It is important to distinguish between the hesitations presented in an initial interview with an unfamiliar adult and the specific deficits found in ASDs. Reluctance to participate may be marked in children with significant anxiety and those whose oppositional or conduct disorders are prominent. Play interviews are entirely appropriate with children in the 6–10 age range and may be particularly revealing. Internal concerns of children are often more amenable to play assessment than to direct questioning.

### **Differential Diagnosis – 6 Years and Older**

Considerable experience and knowledge in working with ASDs are critical clinical issues with older children and adolescents to differentiate ASDs from other diagnostic alternatives. It is important to examine possible factors that have prompted suspicions of an ASD and ask why this child has either (a) presented at this age or (b) not been identified earlier. The clinician must have knowledge of the qualitative and quantitative indicators of ASDs, as well as the developmental expression of behaviors in both typical and atypical development in childhood and adolescence. Because differentiation of psychiatric and co-occurring diagnoses is so vital in this age group, knowledge and/or consultation with specialists are of great benefit.

### **Diagnosing ASDs in Adolescents and Adults**

Occasionally, individuals can remain undiagnosed until adolescence or adulthood, particularly when symptoms are relatively mild (such as with Asperger's Disorder) or when access to health care is limited. Also, some persons may have reached adulthood prior to more widespread awareness of ASDs and remain undiagnosed despite fairly significant symptomatology and otherwise adequate healthcare access. Many of the same issues pertinent to individuals age 6 years or older also pertain to adolescents and adults. However, with increasing age, the record review and the critical elements of early development in the parent/caregiver interview become increasingly challenging. In some cases, this information may be unavailable. Furthermore, the diagnosis can significantly evolve with age in response to therapies and as a result of coping mechanisms to the point of differing significantly from the initial diagnosis (Seltzer et al., 2003). Early developmental history can be critical for establishing a diagnosis, but current behaviors are critical for treatment. Later onset disorders, such as schizophrenia, can share common features with ASDs, but will not be associated with the characteristic early developmental history of ASDs. Therefore, often input from a variety of specialists is critical in the accurate diagnosis of older persons with ASDs. Employment history, capacity for functional independence, and history of social interactions including any potential romantic relationships are additional issues that are important in the histories of older persons.

### **BENEFITS OF COLLABORATION BETWEEN LEAD CLINICIAN AND EDUCATORS**

The diagnostic evaluation for ASDs considers data from multiple sources about the individual's functioning across multiple domains. Best practice recommends that lead clinicians attempt to obtain and allocate adequate time to review relevant records. For many individuals, school records provide valuable information such as a description of strengths and concerns in the school setting, assessment data, and response to attempted interventions. Interviewing a teacher or another educational service provider can offer additional detail regarding specific issues or clarification of information contained in school records. Evaluation of an individual's functioning across settings can be enhanced when parents and teachers complete the same standardized ratings scales, interviews, or other data collection procedures. Some degree of variation between parent and teacher reports is common and can facilitate consideration of variables that influence the individual's functioning.

Parental consent is required for the lead clinician to obtain school records or have educators complete rating scales or interviews. Therefore, at the outset of the evaluation process, the lead clinician discusses the benefits of shared information and encourages parents to provide consent to obtain relevant information and share results of the diagnostic evaluation with appropriate professionals, agencies, and organizations, including schools. In the course of discussing the benefits of sharing information across medical, educational, and other services providers, the lead clinician discusses the overlaps and distinctions between these systems with the family, as appropriate. For example, obtaining parental consent to request school records may provide an appropriate context for clarifying the differences between medical diagnosis and educational eligibility for special education services.

## Key Considerations Related to Differential Diagnosis

Throughout the diagnostic evaluation process, the lead diagnostic clinician collects and integrates data to determine whether an ASD diagnosis is warranted. This requires both collection of sufficient data and clinical skill to differentiate ASDs from other disorders with similar or overlapping presentations, identify which specific ASD diagnosis is most appropriate, and identify difficulties that may coexist with ASDs.

### COMMON DIFFERENTIAL DILEMMAS

Diagnosis of ASDs is based on presentation of specific behaviors and deficits in the domains of communication, reciprocal social interaction, and restricted interests and repetitive behaviors as specified by *DSM-IV-TR* diagnostic criteria. There are several non-autism spectrum disorders that may be associated with difficulties in one or more of these behavioral domains. Symptoms often associated with ASDs may not be specific to ASDs. For example, hand flapping or other repetitive movements may occur in the context of global developmental delay, a stereotypic movement disorder, or intense anxiety. The lead diagnostic clinician is able to differentiate between ASDs and other developmental or psychiatric disorders with overlapping symptoms including:

- disorders associated with multiple areas of difficulty,
- disorders associated with deficits in language and/or communication,
- disorders associated with social interaction problems,
- disorders associated with restricted interests or repetitive behaviors, and
- other disorders associated with ASDs.

### Disorders Associated with Multiple Areas of Difficulty

- |                                |                            |
|--------------------------------|----------------------------|
| ▪ Mental Retardation           | ▪ Schizophrenia            |
| ▪ Reactive Attachment Disorder | ▪ Early Onset Psychosis    |
| ▪ Traumatic Brain Injury       | ▪ Childhood Onset Dementia |

The lead diagnostic clinician is able to differentiate ASDs from cognitive impairment and identify their co-occurrence. Cognitive impairment often co-occurs with ASDs. Therefore, it is important to describe the cognitive abilities of individuals diagnosed with ASDs and determine whether an additional diagnosis of Mental Retardation is warranted. However, individuals with significant cognitive impairment who do not have ASDs may exhibit ASD-like behaviors including social communication deficits and/or motor stereotypies, such as hand-flapping (Bradley, Summers, Wood, & Bryson, 2004; Wing, 1981). Because of this overlap in symptoms, it is difficult to differentiate ASDs from Mental Retardation in children with mental ages below 2 years (Lord, 1995; Rutter & Schopler, 1992). Differential diagnosis requires consideration of how an individual's behaviors relate to his or her overall developmental profile, as well as use of evaluation procedures that identify any behaviors strongly indicative of ASDs (e.g., using another person's hand as a tool). When diagnosis is complicated by possible cognitive impairment, use of standardized instruments to assess cognitive and adaptive functioning, as well as ASD symptoms, is indicated.

Diagnostic evaluation may require differentiation from Reactive Attachment Disorder or Traumatic Brain Injury. In rare cases, evaluation may require differentiation from conditions such as schizophrenia, early onset psychosis, or childhood onset dementia.

#### BEST PRACTICE

The lead clinician is able to differentiate ASDs from other developmental or psychiatric disorders with overlapping symptoms.



### Disorders Associated With Deficits in Language and/or Communication

- Expressive Language Disorder
- Receptive Language Disorder
- Mixed Receptive-Expressive Language Disorder
- Selective Mutism

The lead diagnostic clinician is able to differentiate ASDs from other developmental and psychiatric disorders that also are associated with deficits in language and/or communication. Developmental Language Disorders such as Expressive Language Disorder, Receptive Language Disorder, or Mixed Receptive-Expressive Language Disorder are marked by deficits in the individual's ability to understand or use language or both. Such language deficits may result in social interaction problems because of the individual's frustration with understanding or expressing himself or herself to others. However, language disorders are not associated with idiosyncratic language usage, deficits in social reciprocity, or restricted interests and repetitive behaviors. In addition, individuals with language impairments typically can be distinguished from individuals with ASDs based on intact nonverbal communication. In Selective Mutism, the individual does not speak or communicate in certain settings, but exhibits intact communication in some environments and does not exhibit the marked social impairments and restricted and repetitive behaviors associated with ASDs.

### Disorders Associated with Social Interaction Problems

- Attention Deficit Hyperactivity Disorder
- Social Phobia
- Depression
- Reactive Attachment Disorder
- Personality Disorders

Social interaction and peer relationship problems are a prominent feature of multiple developmental and psychiatric disorders. The lead diagnostic clinician is able to differentiate the impairments in social-emotional reciprocity and social communication that are core features of ASDs from the social difficulties associated with Attention Deficit Hyperactivity Disorder (ADHD), Social Phobia or another anxiety disorder, Depression, Reactive Attachment Disorder (RAD), and Personality Disorders.

### Disorders Associated with Restricted Interests or Repetitive Behaviors

- Stereotypic Movement Disorder
- Tourette's Disorder
- Obsessive Compulsive Disorder

The lead diagnostic clinician is able to determine whether restricted interests or motor stereotypies occur in combination with the deficits in social reciprocity and communication required for an ASD diagnosis or present as a Stereotypic Movement Disorder or in the context of another disorder such as Tourette's or Obsessive Compulsive Disorder (OCD).

### Other Disorders Associated with ASDs

The lead diagnostic clinician is aware of other conditions associated with ASDs (e.g., Non-verbal Learning Disorder, Semantic-Pragmatic Disorder) that are not included in the *DSM-IV-TR* and is able to explain the difference between these labels and medically accepted categories.

## DIFFERENTIATING AMONG ASDs

At the most basic level, differential diagnosis requires a determination of whether the individual's presentation warrants an ASD diagnosis. If an ASD diagnosis is warranted, the lead diagnostic clinician then delineates which *DSM-IV-TR* diagnosis is most appropriate. This requires differentiation among Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). While differentiating among these diagnoses is complicated by the varying interpretations and ongoing revision of diagnostic criteria, determination of a specific *DSM-IV-TR* diagnosis often is essential for accessing services. The lead diagnostic clinician is able to explain the specific diagnosis given and the current debate surrounding distinctions among the three diagnoses within the category of Pervasive Developmental Disorders.

## COMMON COEXISTING DIFFICULTIES

Other psychiatric disorders that require clinical attention can coexist with ASDs. This complicates the clinical picture and requires careful evaluation to identify additional challenges that should be a focus of intervention. These coexisting symptoms may be secondary to the experience of having ASDs such as an individual who develops symptoms of anxiety or depression secondary to social stress. In other cases, psychiatric symptoms may coexist with ASDs as a result of conditions that are interactive rather than sequelae of the disorder. For example, significant cognitive impairment may be a rate-limiting factor in terms of skill acquisition and rate of learning. Other times, coexisting anxiety, depression, obsessive compulsive disorders, and other difficulties reach clinical proportions and themselves become the focus of intervention.

### Disorders that Commonly Coexist with ASDs

- Mental Retardation
- Attention Deficit Hyperactivity Disorder
- Affective Disorders
- Obsessive Compulsive Disorder
- Medical Problems
- Atypical Response to Environment

### MENTAL RETARDATION

ASDs often are associated with some degree of cognitive impairment resulting in a diagnosis of Mental Retardation. Although estimates of the co-occurrence of Autism and Mental Retardation were once as high as 70% to 80% (Bryson & Smith, 1998), current estimates range from 30% to 60% (Chakrabarti & Fombonne, 2005; Shea & Mesibov, 2005). Higher rates of diagnosis of Mental Retardation typically are found among individuals diagnosed with Autistic Disorder, with lower rates among individuals diagnosed with another ASD.

In very young children, the primary challenge related to the overlap and co-occurrence of ASDs and Mental Retardation often is to differentiate among ASDs alone, Mental Retardation alone, and an ASD combined with Mental Retardation. For individuals diagnosed with ASDs who have mild global impairments, the possibility of a diagnosis of Mental Retardation may not emerge until the child enters or progresses through elementary school and differences from same-age peers become more pronounced. In cases where the possibility of Mental Retardation complicates diagnosis, use of standardized instruments to assess cognitive and adaptive functioning as well as ASD symptoms is indicated.

### ATTENTION DEFICIT HYPERACTIVITY DISORDER

It is not uncommon for an individual diagnosed with an ASD to exhibit significant difficulties with symptoms associated with Attention Deficit Hyperactivity Disorder (ADHD) including poor attention regulation, hyperactivity, and impulse control (Gadow, DeVincent, & Pomeroy, 2006; Reiersen, Constantino, Grimmer, Martin, & Todd, 2008). ADHD symptoms or executive functioning deficits often are conceptualized as part of ASDs

although not all individuals with ASDs exhibit significant impairments in these areas. Current *DSM-IV-TR* diagnostic criteria disallow a diagnosis of ADHD in individuals with an ASD diagnosis; however, recognition that ADHD symptoms can create additional impairments or heighten existing impairments in individuals with ASDs has influenced many professionals to treat dual diagnosis of ASDs and ADHD as an acceptable clinical practice.

#### AFFECTIVE DISORDERS

Affective disorders including depression and anxiety are among the most common coexisting disorders found in individuals with ASDs. The etiology of risk in individuals with an ASD for coexisting affective disorders is unclear (Volkmar & Klin, 2000). Individuals at higher levels of cognitive functioning often are included academically with more socially adept, typical peers. In the absence of supports, these individuals are at increased risk for social rejection, which can cause substantial frustration, anxiety, and stress. Such difficulties will increase in later childhood, adolescence, and young adulthood when social competence is more critical to successful adaptation. In these instances, increased rates of affective disorders may be seen as secondary to significant social disability.

There may be a link between some affective disorders and ASDs. This has been most commonly reported in Asperger's Disorder and PDD-NOS. For example, Kim et al. (2000) identified higher rates of mood and anxiety problems among higher functioning children with autism and Asperger's Disorder. A significant proportion of these children presented with difficulties in the clinical range. Enhanced well being and functioning of the child or adolescent is incumbent upon the accurate identification and treatment of these coexisting challenges.

#### OBSESSIVE COMPULSIVE DISORDER

Although features of Obsessive Compulsive Disorder (OCD) may be mistaken for restricted interests and repetitive behaviors associated with ASDs, it is possible for an individual with an ASD to present with additional symptoms consistent with a diagnosis of OCD.

#### MEDICAL PROBLEMS

Medical issues associated with ASDs include consideration of both general health issues and the possible cause or etiology of the ASD itself. Associated health problems include pica with possible lead ingestion, poor nutritional status secondary to restricted food preferences, obesity, gastrointestinal complaints such as chronic constipation or diarrhea, sleep difficulties, and seizures. The possibility of an identifiable biological cause of the ASD also requires careful consideration and an individualized assessment for possible neurological, genetic, and metabolic etiologies. These topics are considered in greater detail in Chapter Four in the section on the Comprehensive Medical Examination.

#### ATYPICAL RESPONSE TO ENVIRONMENT

Individuals with ASDs often exhibit atypical responses to their environments such as unusual sensory preferences or aversions. Atypical responses to the environment often may be conceptualized as part of the diagnostic criteria related to restricted interests or repetitive behaviors. Atypical sensory responses are discussed in greater detail in Chapter Four in the section on Assessment of Motor and Sensory Functioning.

# Formulating Conclusions and Presenting Information

The second half of the diagnostic process involves formulating conclusions and presenting information to the family and other service providers.

After reaching a diagnostic conclusion, the lead diagnostic clinician should discuss evaluation results with the individual's family. A family-centered evaluation entails spending sufficient time with parents to provide detailed feedback and answer all questions.

In order to provide thorough feedback, the lead diagnostic clinician must be able to:

- clarify the distinction between diagnostic evaluation and assessment for intervention planning;
- explain the diagnostic conclusion and the procedures used to arrive at that conclusion;
- interpret treatment options and prognosis, and make referrals for further assessment for intervention planning within the parameters of empirical research findings;
- inform the family of the differences between the medical diagnosis and educational and community-based program eligibility processes;
- communicate findings across disciplines;
- address issues that affect parents directly; and
- provide diagnostic conclusions and recommendations related to available supports and resources, further assessment, and intervention as soon after the evaluation is completed as possible.

## BEST PRACTICE

**A family-centered evaluation entails spending sufficient time with parents to provide detailed feedback and answer all questions.**

## DISTINCTION BETWEEN MEDICAL DIAGNOSIS AND EDUCATIONAL ELIGIBILITY

Diagnostic evaluation is conducted to determine if an individual meets medical criteria for an ASD in order to inform treatment recommendations, whereas school-based evaluations are conducted to determine if a child requires special education services in order to make acceptable academic progress based on educational eligibility criteria.

## KEY ELEMENTS OF PROVIDING FEEDBACK TO FAMILIES

The lead clinician discusses evaluation results with families in a manner that is honest and compassionate. During feedback, the lead clinician attends to the following key elements:

- providing specific information about the individual characteristics and behaviors that warrant a diagnosis along with examples of how these concerns interfere with the individual's functioning;
- emphasizing individual assets and areas of typical development;
- answering questions about prognosis based on available research, professional experience, and the individual's unique profile;
- highlighting the significant role of parent involvement and advocacy in determining prognosis; and
- collaborating with families to determine next steps including:
  - beginning to identify a team of professionals with whom they will work on an ongoing basis,
  - developing a plan for follow-up,
  - providing referrals for assessment for intervention planning or intervention services as needed,
  - providing recommendations of a few basic resources, and
  - offering suggestions for addressing any pressing concerns such as specific behavioral challenges.

## DOCUMENTATION: FORMULATE A WRITTEN REPORT

A written report should be provided to the individual's family and the initial referral source. Written documentation serves as an essential means of communication between the clinician and the family and between the diagnosing clinician and other professionals who are involved with assessing the child for intervention planning and providing intervention services or future follow-up evaluation. In addition, written documentation often is essential for accessing services such as special education or state-funded programs.

### COMPONENTS OF THE WRITTEN REPORT

#### Clinical Data

- A description of the diagnostic process, any diagnostic instruments used, diagnostic conclusions, and the data obtained via record review, parent interview, and direct behavioral observation and interaction that support making or ruling out the diagnosis
- Description of individual strengths or areas of typical development noted in the diagnostic evaluation process
- Specific descriptors related to the triad of impairments specified in diagnostic criteria for ASDs, as well as information about the child's developmental level, adaptive functioning, and presentation of any maladaptive behaviors
- Diagnostic conclusions that are supported with sufficient detail so that they can be readily understood by another professional
- Quantitative and qualitative evaluation data that would allow an experienced reviewer to readily verify the diagnosis or the reasons it was ruled out

#### Next Steps

- Appropriate referrals for services and additional assessment needed for intervention planning
- Basic resources on ASDs for family reference
- Follow-up plan

#### Community Collaboration

- Clear explanation that the evaluation provides a medical diagnosis and that eligibility for social or educational services may have different or additional criteria that require further evaluation
- Whenever possible, partnership of the lead diagnostic clinician with schools and other service providers to document information obtained during the diagnostic evaluation process that may be relevant to eligibility decisions
- Diagnostic conclusions formulated to facilitate translation into educational or other agency terminology
- Overall evaluation report that is comprehensible to parents and social, habilitative, or educational staff to facilitate enrollment in educational or service programs for eligible individuals

#### BEST PRACTICE

Evaluation reports are written in a manner that is accessible and understandable to parents and the other service providers who may be involved in providing therapeutic, educational, social, or habilitative services.

#### BEST PRACTICE

Parents are encouraged to share the written evaluation report with other professionals who are providing ASD-related services, as appropriate.

## FORMAL DIAGNOSTIC CODES PROVIDE A COMMON LANGUAGE AND ACCESS TO SERVICES

The use of formal diagnostic codes provides a common language for other professionals who may become involved with the child or young adult and his or her family and assists in access to service delivery systems. Third-party payers typically require use of formal diagnostic codes for approval, documentation, and reimbursement of services. In addition to providing diagnostic criteria, as previously discussed, the *DSM-IV-TR* also is one of the primary classification systems used for assigning a specific diagnosis and an accompanying diagnostic code. In addition, many healthcare settings use diagnostic codes derived from another diagnostic manual, the *International Classification of Diseases, Ninth Revision (ICD-9)* published by the World Health Organization. Because of collaboration between the developers, the same codes are used for diagnoses contained in both the *DSM-IV-TR* and the current *ICD* codes used in the United States (*ICD-9-CM*). Diagnostic impressions should not be limited to provision of a diagnosis and its accompanying code but also may include further qualifying information or nonstandard diagnostic nomenclature.

These *Guidelines* acknowledge the controversy and dissatisfaction with the adequacy of *DSM-IV-TR* diagnostic categories and their ability to capture variability among individuals with ASDs. Work on the next edition of the *DSM* is currently underway and substantial revisions related to ASDs are expected. At present, some alternate classification systems are available, such as the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood (DC 0-3R)*, which describes additional diagnostic categories that are particularly relevant to children under 3 years of age (Zero to Three, 2005). However, the *DC 0-3R* diagnostic codes are not widely accepted, and many of the categories are descriptive in nature and limited to describing difficulties in specific developmental domains.



# Assessment for Intervention Planning

## CHAPTER 4



## Introduction

This chapter discusses *assessment for intervention planning* as part of an integrated process designed to promote early identification of ASDs and expedite access to a full range of community-based services. *Diagnostic evaluation*, as discussed in detail in Chapter Three of these *Guidelines*, answers the question, “Is an ASD diagnosis warranted?” In contrast, *assessment for intervention planning* answers the question, “What individual strengths and concerns should guide intervention planning?”

In this document, diagnostic evaluation and assessment for intervention planning are discussed separately for clarity and applicability across settings. Although diagnostic evaluation and assessment for intervention planning may occur simultaneously, it is not essential that both steps be completed at the same time. Even in cases where the diagnostic process involves professionals from more than one discipline, additional assessment may be needed to inform intervention planning.

This chapter is divided into two sections. Additional information regarding the instruments used in assessment for intervention planning is included in Appendix G.

**SECTION ONE** provides an overview of assessment for intervention planning including:

- importance of partnering with families;
- importance of community collaboration;
- individual strengths and concerns guide intervention planning;
- clinical assessment for intervention planning;
- essential components of assessment for intervention planning;
- talking to parents about findings;
- formulation of the written report; and
- enhancing community collaboration.

**SECTION TWO** provides a more in-depth discussion of the technical aspects of assessment for intervention planning in each of the essential components:

- cognitive and academic functioning;
- adaptive functioning;
- social, emotional, and behavioral functioning;
- communication;
- comprehensive medical examination;
- sensory and motor functioning; and
- family functioning.

## SECTION ONE

# Importance of Partnering with Families

These *Guidelines* emphasize that individuals with ASDs are part of larger family systems. The individual's unique profile of strengths and concerns is considered in the context of the family's priorities and resources, which help to guide the assessment for intervention planning process. Multiple developmental domains are affected by ASDs and there is variability of severity of impairments among individuals with ASDs; therefore, collaboration with family members is particularly important in prioritizing the domains to be addressed. Intervention planning should be based on family concerns, the individual's current levels of functioning, and the family's access to resources, as well as clinical factors, intervention history, and the results of prior assessments.

### BEST PRACTICE

**Assessment for intervention planning requires collaboration with family members to prioritize domains of functioning to be addressed based on family concerns, functioning, and access to resources as well as clinical factors, intervention history, and prior assessment results.**

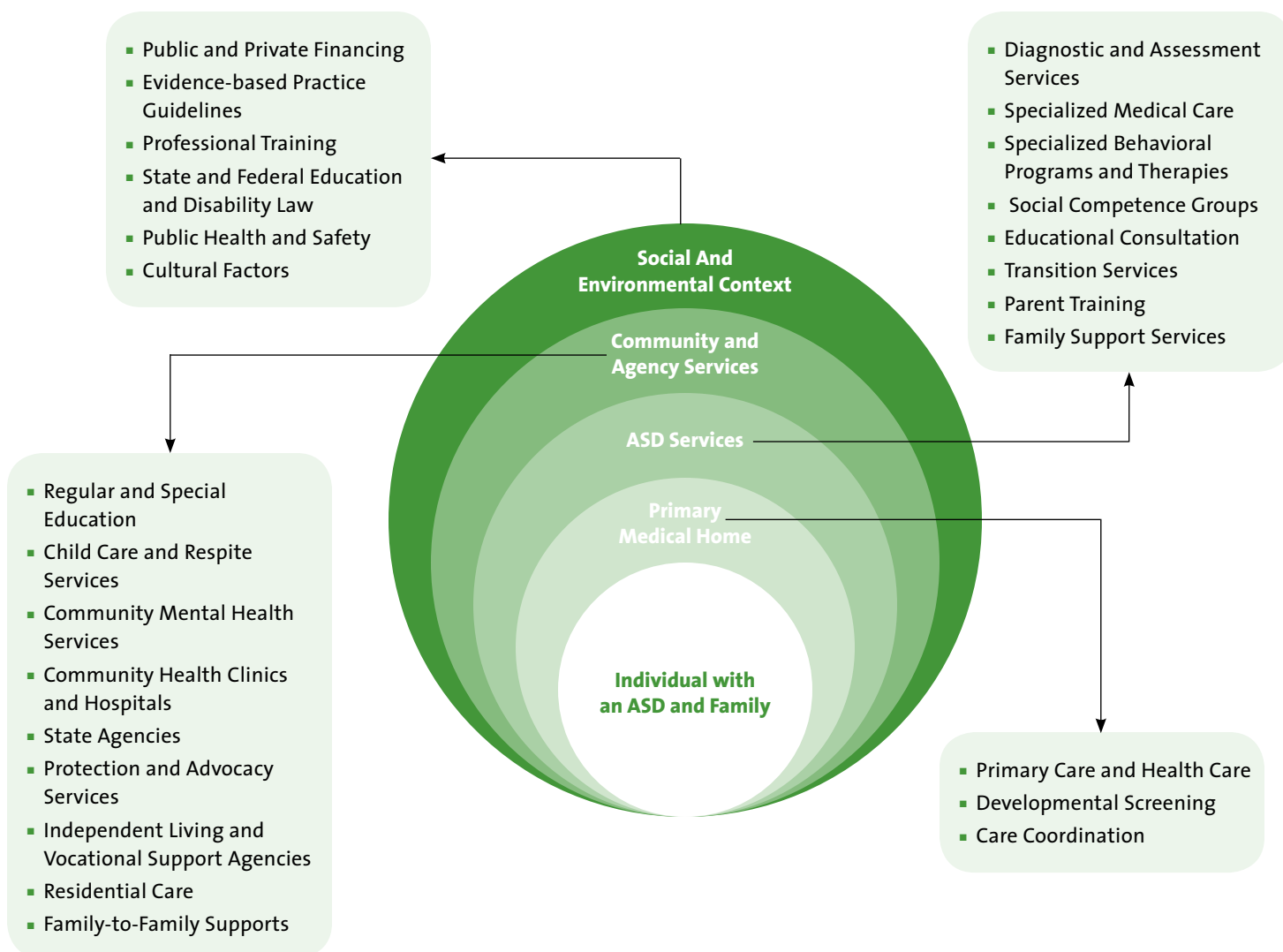
# Importance of Community Collaboration

Because of the multiple developmental domains impacted by ASDs, comprehensive assessment for intervention planning requires participation of professionals from multiple disciplines and typically involves multiple service delivery systems including medical, educational, and other community-based services. As described in Chapter One, each service delivery system has its own set of procedures for diagnosis or eligibility determination and assessment for intervention planning (for a comparison of clinical/medical, educational, and other service system assessments, see Table 1.2 on page 17). Therefore, just as individuals with ASDs are part of larger family systems, the individual and the family are part of a larger framework of ongoing and integrated services that include health care, education, and community-based services in the context of current social and environmental factors (see Figure 4.1). These *Guidelines* promote interdisciplinary and interagency communication and collaboration among the referred individual, the family, and the various components of the service delivery system.

Although these *Guidelines* focus primarily on *clinical/medical* assessment (or clinical assessment) for intervention planning, collaboration among clinical, school, and community-based professionals is vital to comprehensive planning for intervention. Clinical assessment procedures are enhanced when data from eligibility evaluations are considered and assessments are completed to guide educational or other intervention planning. Educational professionals and other service providers involved with a child can contribute valuable information about the individual's functioning in different environments and responsiveness to attempted interventions. Reviewing data from educators and other service providers often allows clinical assessment to focus in more detail on specific aspects of the individual's functioning. Likewise, assessment for intervention planning in educational and other community-based settings is enhanced when consideration is given to the results of clinical assessment and the insights of clinical service providers.

## COMMUNITY COLLABORATION MODEL

FIGURE 4.1



### BEST PRACTICE

**Professionals involved in assessment for intervention planning understand the basic similarities and distinctions among the various service systems including medical, educational, and other providers with which individuals with ASDs and their families may be involved.**

Gaps in communication and lack of collaboration among service systems are identified consistently as a cause of significant confusion and challenges for individuals with ASDs and their families. Therefore, it is essential for professionals involved in assessment for intervention planning to understand the basic similarities and distinctions among the various service systems with which the family may be involved. Professionals can use this knowledge to collaborate with families and practice in a manner that enhances interagency and interdisciplinary collaboration. The benefits of sharing information across service systems are explicitly discussed with families, and parents are encouraged to provide consent to obtain and release relevant information to other professionals, agencies, and organizations, including schools.

# Individual Strengths and Concerns Guide Intervention Planning

Assessment for intervention planning answers the question, “What individual strengths and concerns should guide intervention planning?” Although a diagnosis indicates a cluster of individual characteristics that fit in a specific category, has treatment implications, and is necessary for access to many services, a diagnosis does not capture the diversity in expression of symptoms and level of functioning among individuals diagnosed with ASDs. As a result, diagnosis alone typically is not sufficient for service providers to identify and individualize needed intervention services. Assessment for intervention planning builds on the diagnostic evaluation by further describing the strengths and concerns of the individual that fit within the diagnostic category. Assessment requires careful examination of the individual’s functioning across multiple domains with the express objective of directing intervention planning based on the individual’s unique profile of strengths and concerns.

As discussed in further detail below, assessment for intervention planning includes consideration of the following *essential components* for each individual:

- cognitive and academic functioning;
- adaptive functioning;
- social, emotional, and behavioral functioning;
- communication;
- comprehensive medical examination;
- sensory and motor functioning; and
- family functioning.

The *goals* of comprehensive clinical assessment for intervention planning are to:

- determine areas in which additional information is needed and facilitate referrals or consultation to obtain any needed information;
- identify the individual’s strengths and concerns across relevant domains in the context of family functioning, clinical indicators, intervention history, prior assessment data, and the community setting;
- evaluate for associated medical concerns and possible biological causes of the ASD; and
- develop an intervention plan that addresses the unique strengths and concerns of the individual and his or her family within the community.

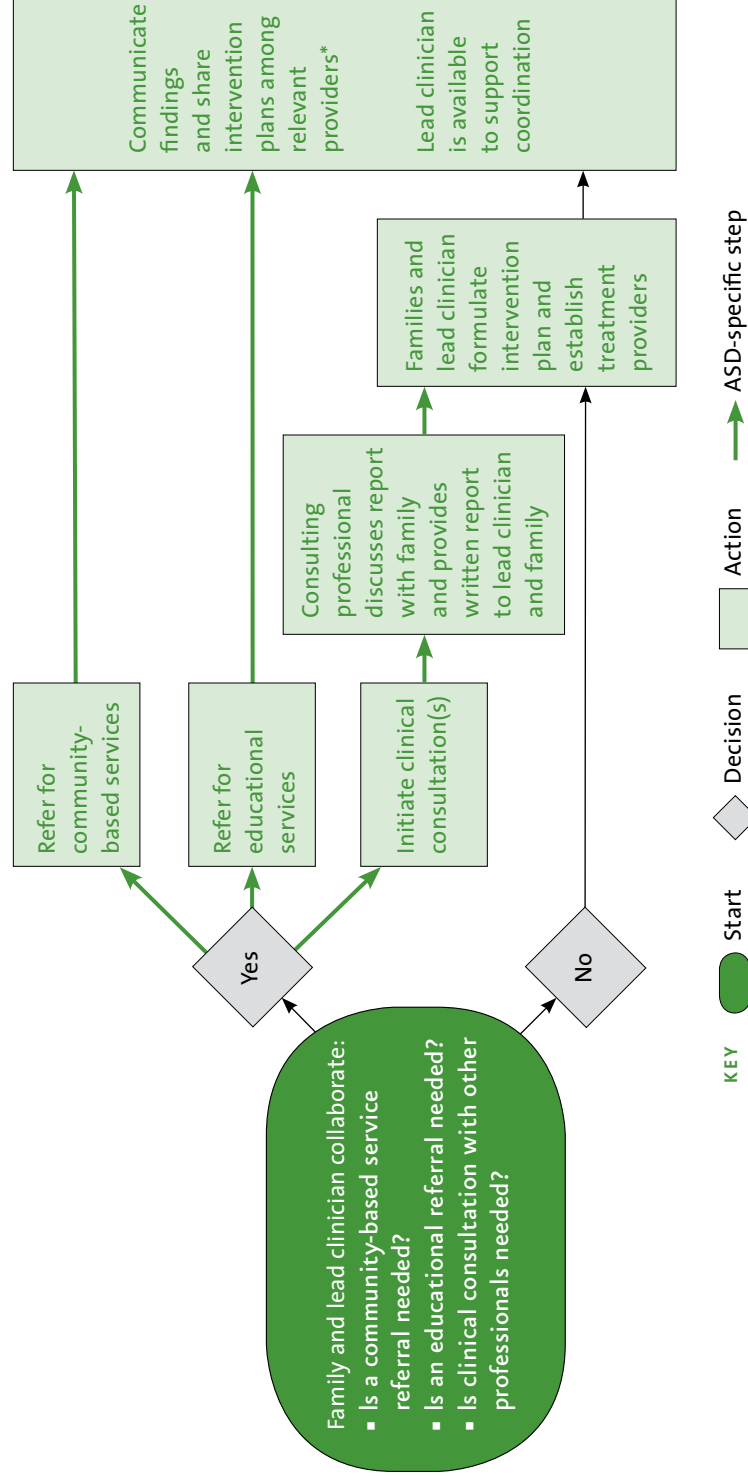
The process to achieve these goals is summarized in Figure 4.2.

## BEST PRACTICE

**Assessment requires careful examination of individual functioning across multiple domains to direct intervention planning based on the individual’s unique profile of strengths and concerns.**

## THE ASSESSMENT FOR INTERVENTION PLANNING PROCESS

FIGURE 4.2



### BEST PRACTICE

After initial assessment for intervention planning has been completed, the lead clinician remains available to the family to support coordination of care.

### BEST PRACTICE

Community collaboration is enhanced when results of clinical, educational, and other community-based assessments are available for consideration across settings and service providers.

After an individual has been diagnosed with an ASD, the lead diagnostic clinician facilitates the transition to assessment for intervention planning. In some cases, the lead diagnostic clinician may continue to take the lead during the assessment process, whereas in other cases the lead diagnostic clinician may refer the family to another provider who can coordinate the assessment for intervention planning process. The clinician coordinating the assessment for intervention planning process collaborates with the individual with an ASD and his or her family to determine the need for referrals related to educational or other services and whether consultation with other professionals is needed to inform intervention planning.

If warranted, the lead clinician initiates consultation with one or more professionals representing the relevant disciplines. Consulting professionals complete an assessment, discuss their findings with the family, and provide a written report summarizing their findings to the family and the lead clinician in a timely manner. Based on all relevant information, the lead clinician collaborates with the family to formulate an intervention plan and establish treatment providers. The lead clinician remains available to the family to support coordination of care.

The lead clinician also obtains informed consent and collaborates with the family to identify providers with whom assessment findings and intervention plans are to be shared. Community collaboration is enhanced when clinical assessment results are formulated in a manner that facilitates their use across clinical, educational, and community settings. Similarly, a greater degree of communication and coordination occurs when results of educational and community-based assessments are available for consideration across settings and service providers.

Although this chapter addresses the initial assessment for intervention planning that takes place after an individual has received an ASD diagnosis, it is important to recognize that assessment is a continuous and ongoing process. After initial intervention plans are developed, ongoing assessment occurs to monitor the individual's progress and update intervention strategies and goals as needed.

#### BEST PRACTICE

Professionals involved in assessment for intervention planning understand the role of assessment in development of an initial intervention plan and the need for continuous and ongoing assessment.

## Clinical Assessment for Intervention Planning

### MISSOURI'S TIERED APPROACH TO DIAGNOSTIC EVALUATION

The clinician and the family review the data gathered through the diagnostic evaluation process to determine whether additional information is needed for intervention planning. In Missouri's tiered approach to diagnostic evaluation, the extent of additional clinical assessment needed for intervention planning is directly related to whether the diagnostic evaluation was completed at Tier 1, Tier 2, or Tier 3.

#### Tier 1

Diagnostic evaluations completed by independent professionals often focus primarily on individual functioning in the domains required to confirm an ASD diagnosis and provide limited information for intervention planning. Typically, an individual diagnosed based on a Tier 1 evaluation will require a referral to an interdisciplinary team or referrals to multiple professionals for assessment for intervention planning. For example, if an individual is diagnosed independently by a physician, the physician arranges consultation with or makes referrals to a team or to multiple professionals for assessment of areas such as cognitive and adaptive functioning.

#### Tier 2

Diagnostic evaluations, including the use of standardized instruments and/or collaboration among professionals from two or more disciplines, typically provide some of the assessment data needed for intervention planning. For example, if an individual is diagnosed by a physician-psychologist team, comprehensive medical examination and assessment of cognitive and adaptive functioning may have been completed during the diagnostic evaluation. Referrals may be needed for assessment of communication and sensory and motor functioning.

#### Tier 3

Diagnostic evaluation and assessment for intervention planning often occur simultaneously when an individual is evaluated by a team of professionals. In such cases limited, if any, referrals may be needed for additional assessment to inform intervention planning. For example, if a diagnostic evaluation includes assessment by a physician, psychologist, speech-language pathologist, and occupational therapist, additional assessment may not be needed for intervention planning. In some cases, additional referrals may be needed to professionals such as a psychiatrist, neurologist, geneticist, behavior analyst, or vocational rehabilitation specialist.



# Essential Components of Assessment for Intervention Planning

Although a diagnosis of an ASD confirms impairments in reciprocal social interaction and communication and/or restricted interests and repetitive behaviors, further assessment beyond basic diagnostic evaluation is needed to identify an individual's strengths and concerns within each of these areas to inform intervention planning. Therefore, assessment for intervention planning includes assessment of social, emotional, and behavioral functioning as well as communication skills. In addition, as neurobiological disorders, ASDs have multiple causes, frequently associated medical concerns, and the potential to impact an individual across multiple additional domains including cognitive, adaptive, and sensory and motor functioning. Although not explicitly necessary for making a diagnosis, assessment in these domains is necessary for informed management and treatment of an ASD. Thus, it is possible for an independent professional or professionals representing one or two areas of expertise to make an ASD diagnosis, but assessment for intervention planning requires involvement of professionals representing multiple disciplines.

## BEST PRACTICE

Assessment for intervention planning requires involvement of professionals representing multiple disciplines.

All individuals diagnosed with ASDs are assessed in the following domains: cognitive and academic; adaptive; social, emotional, and behavioral; communication; medical; sensory and motor; and family functioning. This list is intended to provide guidance for the key areas to be assessed to inform intervention planning; it is not an exhaustive list. (See Table 4.1 for additional information.)

The lead clinician collaborates with the family in each individual case to determine the need for assessment related to each essential component based on:

- **Family concerns, functioning, and resources.** In collaborating with the family to plan for any needed assessment, the lead clinician listens to the family's concerns and collects other relevant family information.
- **Clinical indicators.** The lead clinician discusses any clinical indicators that suggest a need for specific follow-up. Although some aspects of assessment, such as assessment of cognitive and adaptive functioning and medical concern, are indicated in all cases; other referrals are based on specific aspects of individual's presentation.
- **The individual's intervention history.** The lead clinician reviews the individual's intervention history with the family in determining the need for referrals or consultation with other professionals at the outset of the assessment for intervention planning process. For example, if an individual is actively participating in speech and language therapy, then additional assessment in this domain may not be needed or very specific assessment needs may be identified.
- **Data available from prior assessments.** The lead clinician reviews data from prior assessments with the family to determine the need for referrals or consultation with other professionals at the outset of the assessment for intervention planning process. Data are considered from prior clinical assessments, medical evaluations, and previous assessments completed in educational and other community settings.

## BEST PRACTICE

Professionals involved in clinical assessment for intervention planning have expertise in their fields and specific training and experience with ASDs. Professionals openly discuss their credentials and experience with ASDs with individuals involved in the assessment process including parents or other family members.

## BEST PRACTICE

Individuals with ASDs, their families, and/or advocates are encouraged to inquire about the training and experience of professionals when selecting service providers.

**ESSENTIAL COMPONENTS OF ASSESSMENT FOR INTERVENTION PLANNING**

TABLE 4.1

<b>ASSESSMENT OF COGNITIVE AND ACADEMIC FUNCTIONING</b>	<ul style="list-style-type: none"> <li>▪ Child’s current developmental level or level of cognitive functioning</li> <li>▪ Review of any prior cognitive testing that may indicate changes over time</li> <li>▪ Academic and/or pre-academic skills, as indicated</li> <li>▪ Neuropsychological functioning, as indicated</li> </ul>
<b>ASSESSMENT OF ADAPTIVE FUNCTIONING</b>	<ul style="list-style-type: none"> <li>▪ Level of day-to-day functioning in domains relevant to the individual’s developmental level</li> </ul>
<b>ASSESSMENT OF SOCIAL, EMOTIONAL, AND BEHAVIORAL FUNCTIONING</b>	<ul style="list-style-type: none"> <li>▪ Overall level of social, emotional, and behavioral functioning including impact of ASD symptoms</li> <li>▪ Coping and social problem-solving skills</li> <li>▪ Social vulnerability and any experiences of victimization</li> <li>▪ Symptoms of other mental health conditions</li> <li>▪ Presence or history of any self-harm or suicidal ideation</li> <li>▪ Description or functional analysis of challenging behaviors</li> </ul>
<b>ASSESSMENT OF COMMUNICATION</b>	<ul style="list-style-type: none"> <li>▪ Assessment of relevant domains of speech and language functioning as well as communication and pragmatic language</li> </ul>
<b>COMPREHENSIVE MEDICAL EXAMINATION</b>	<ul style="list-style-type: none"> <li>▪ Comprehensive health history, including review of systems</li> <li>▪ Definitive hearing and vision examinations</li> <li>▪ General physical and dysmorphology examinations</li> <li>▪ Neurodevelopmental examination</li> <li>▪ Laboratory tests and/or neuroimaging, as indicated</li> </ul>
<b>ASSESSMENT OF SENSORY AND MOTOR FUNCTIONING</b>	<ul style="list-style-type: none"> <li>▪ As indicated, assessment of fine and gross motor skills, feeding and oral motor skills, and sensory functioning</li> <li>▪ Assessment of sensory functioning with specific attention to both negative reactions to and strong preferences for specific sensory stimuli</li> </ul>
<b>ASSESSMENT OF FAMILY FUNCTIONING</b>	<ul style="list-style-type: none"> <li>▪ Level of parenting stress</li> <li>▪ Impact on siblings and family functioning</li> <li>▪ Extent of family’s support network</li> <li>▪ Resources accessed and of interest</li> <li>▪ Financial impact of ASD diagnosis</li> <li>▪ Legal considerations</li> </ul>

**BEST PRACTICE**

Professionals involved in assessment for intervention planning consider available data from all prior assessments including assessments conducted in clinical, educational, or other service settings.

**BEST PRACTICE**

Although each essential component is explored for all individuals diagnosed with ASDs, assessment for intervention planning is tailored to the unique needs of each individual and his or her family.

A brief overview of each of the essential components is provided below. Each overview includes a definition of the component (indicated in bold) being discussed.

For a more detailed discussion of the technical aspects of assessment in each of these domains, please refer to Section Two of this chapter. Professionals involved in clinical assessment of the following domains for intervention planning have expertise in their fields and specific training and experience with ASDs.

### **Assessment of Cognitive and Academic Functioning**

**Cognitive functioning** refers to an individual's ability to process information using skills such as verbal and nonverbal reasoning, problem solving, classification, sequencing, working memory and processing speed.

Assessment of cognitive functioning is completed for all individuals diagnosed with ASDs to determine the individual's overall level of cognitive functioning including any specific strengths or concerns. In some cases, cognitive assessment occurs during the diagnostic evaluation process because the lead diagnostic clinician determines that information about an individual's level of cognitive functioning is crucial to differential diagnosis (e.g., a Tier 1 or Tier 3 evaluation). If cognitive assessment has not been completed prior to or as part of the diagnostic evaluation process, then the lead diagnostic clinician makes a referral for cognitive assessment as part of the assessment for intervention planning process.

The goal of assessment of cognitive functioning is to gain insight into the individual's ability to solve problems, apply and process information, and tolerate structured learning demands, as well as to identify the individual's overall level of functioning and specific cognitive strengths and concerns. Cognitive assessment aids in identification of co-occurring impairments (e.g., a diagnosis of Mental Retardation) and provides important information about prognosis. (In these *Guidelines* the term Mental Retardation is used for a specific diagnostic classification based on the terminology in *DSM-IV-TR*.) Over time, an individual's pattern of performance on cognitive measures is examined for evidence of changes in level of functioning that may be related to the increasing complexity of age-based expectations, increasing or decreasing gaps in skills compared to same-age peers, or loss of skills.

**Academic functioning** refers to the individual's current educational functioning including acquisition of educational skills in areas such as reading, mathematics, and written expression. The lead clinician considers the need for assessment of academic skills during the clinical assessment for intervention planning with specific attention to data available from any school-based evaluations. Academic testing is an integral part of educational assessment for intervention planning and is often completed through the educational system to inform decisions about eligibility for special education services and related goals and services. In some cases, academic assessment may be indicated during the clinical assessment for intervention planning process to provide further information about the individual's profile of strengths and concerns; to facilitate identification of co-occurring difficulties; to consider any discrepancies in reasoning, adaptive, and academic skills; or to inform transition planning. In some cases, neuropsychological assessment may be used to complement and further integrate results of cognitive or academic assessment.

#### **BEST PRACTICE**

**Assessment of cognitive and academic functioning is completed for all individuals diagnosed with ASDs.**

### Assessment of Adaptive Functioning

**Adaptive functioning** refers to capacities for personal and social self-sufficiency and problem solving in real world situations, including functioning in the areas of communication, fine and gross motor skills, daily living skills, community living skills, social and emotional functioning, and transition to higher education, employment, and independent or supported living. If adaptive functioning has not been assessed prior to or as part of the diagnostic evaluation, it is completed for all individuals diagnosed with ASDs to assess the individual's overall level of adaptive functioning and specific adaptive strengths and concerns. In some cases, assessment of adaptive functioning occurs during the diagnostic evaluation process because the lead diagnostic clinician determines that information about an individual's level of adaptive functioning is crucial to differential diagnosis (e.g., a Tier 2 or Tier 3 evaluation). Research indicates that individuals with ASDs often exhibit patterns of adaptive deficits that may aid diagnosis and exist independently of levels of cognitive functioning or ASD severity. Adaptive skill profiles typically are uneven with relatively better performance on motor and daily living skills than in socialization and communication.

Assessment of adaptive functioning is essential for individuals diagnosed with ASDs because it provides information about the person's typical functioning in home, school, and community settings. Results may differ markedly from information obtained through formal assessment. Adaptive deficits can be easily overlooked in individuals who exhibit cognitive strengths. Large gaps between cognitive ability and adaptive levels clarify areas to target for intervention and highlight the need for learning to occur in naturalistic settings.

### Assessment of Social, Emotional, and Behavioral Functioning

**Social, emotional, and behavioral functioning** is a broad category that refers to understanding and self-regulation of interpersonal interactions, affective responses, and behavior, including the impact of ASD symptoms on interpersonal, affective, and behavioral awareness and self-regulation; coping and social problem-solving skills; challenging behaviors; symptoms of specific mental health conditions; presence or history of any self-harm or suicidal ideation; and social vulnerability and experiences of victimization.

Comprehensive assessment of social, emotional, and behavioral functioning is completed for all individuals diagnosed with ASDs to answer the question, "What are the individual's social, emotional, and behavioral strengths and concerns?" Social, emotional, and behavioral functioning are necessarily considered as a part of all diagnostic evaluations due to their prominence in ASD diagnostic criteria and for diagnostic differentiation; however, the depth and breadth of attention to these domains during the diagnostic process varies based on the tier of the evaluation, the presentation of the individual, and the specific professionals involved. The lead clinician collaborates with the family to determine if additional social, emotional, or behavioral assessment is needed as part of the clinical assessment for intervention planning process.

### ASSESSMENT OF SOCIAL FUNCTIONING

After an ASD diagnosis has been given, additional assessment of social functioning may be needed to further describe the individual's specific social impairments and their impact on his or her daily functioning. In cases where a standardized instrument was not used during the diagnostic evaluation to assess ASD-related social impairments, such an instrument may be used during the assessment for intervention planning process.

#### BEST PRACTICE

**Assessment of adaptive functioning is completed for all individuals diagnosed with ASDs.**

#### BEST PRACTICE

**For older children, adolescents, and young adults, assessment of adaptive functioning includes attention to skills and competencies required for transitions, such as transition from elementary to middle school or from home to supported or residential living.**

#### BEST PRACTICE

**Assessment of social, emotional, and behavioral functioning includes consideration of possible coexisting social-emotional difficulties that might impact intervention planning.**

#### ASSESSMENT OF CO-EXISTING SOCIAL AND EMOTIONAL DISORDERS

Careful consideration is given to the possibility of co-existing social and emotional disorders such as anxiety or depression that might impact intervention planning. Assessment is completed to validate or rule out any additional diagnoses that are suspected based on parental concern, prior evaluation results, or clinical impressions. Comprehensive assessment of social and emotional functioning helps to identify symptoms that will become the focus of intervention.

Regardless of the instruments or procedures utilized, specific questions are asked about any suicidal ideation or other self-injurious behaviors.

#### ASSESSMENT OF CHALLENGING BEHAVIORS

Individuals with ASDs often display challenging behaviors that interfere with family functioning and significantly limit participation in the community. These behaviors often are a major source of family stress in terms of strain on family relationships, emotional well-being, and finances. Priority is given to addressing the family's behavioral concerns and promoting functional skills in the individual with an ASD.

Behavioral assessment takes into account the range of variables that may be associated with problem behaviors, including communication failures, environmental stressors, need for routine and structure, gaining attention or access to objects or activities, or escaping a non-preferred task or situation.

#### BEST PRACTICE

**Comprehensive assessment of social, emotional, and behavioral functioning is completed for all individuals diagnosed with ASDs.**

#### ASSESSMENT OF SOCIAL VULNERABILITY AND VICTIMIZATION

Individuals with ASDs are at risk for increased social vulnerability and victimization because of deficits in social insight, pragmatic language, and behavioral regulation. Assessment of social-emotional functioning includes specific questions about the individuals' ability to perceive risky social situations and to remove themselves from dangerous situations and any specific experiences of victimization. Topics covered should include verbal, physical, and sexual harassment and assault.

#### Assessment of Communication

**Communication** refers to all forms of sending and receiving messages, including spoken language, gestures, body language, sign language, or via an assistive device.

Comprehensive assessment of communication skills is completed for all individuals diagnosed with ASDs to provide information about long-term prognosis and facilitate planning of communication interventions. It answers the question, "What are the individual's overall levels of functional communication and specific communication strengths and concerns?" Communication is necessarily considered as a part of all diagnostic evaluations because it is one of three areas of impairment that define ASDs; however, the depth and breadth of attention to communication during the diagnostic process varies based on the Tier of the evaluation, the presentation of the individual, and the specific professionals involved. The lead clinician collaborates with the family to determine if additional communication assessment is needed as part of the clinical assessment for intervention planning process.

#### BEST PRACTICE

**Comprehensive assessment of communication skills is completed for all individuals diagnosed with ASDs.**

### Comprehensive Medical Examination

A **comprehensive medical exam** includes the following: a review of medical records to be certain that appropriate vision and hearing testing have been performed, a standard health history, a physical examination including an assessment for dysmorphology (i.e., atypical physical features of facial or body structures indicative of abnormal processes occurring during embryogenesis), and a neurological examination. The medical assessment answers the question, “Does the individual show evidence of associated medical conditions or an identifiable biological etiology for his or her impairments?” It focuses on two separate issues:

1. the presence of medical conditions that require additional medical evaluation or therapy, and
2. the possible cause or etiology of the ASD itself.

Determination of associated medical conditions and etiology has many potential benefits. The approach can assist in the selection of medical therapies as well as in the identification of an underlying etiology that may direct the therapeutic plan and inform recurrence risk assessment.

Medical conditions associated with ASDs include:

- Vision and Hearing Impairments
- Sleep Disorders
- Gastrointestinal Conditions
- Nutritional Deficiencies
- Seizures

#### BEST PRACTICE

**All individuals diagnosed with ASDs require a comprehensive medical examination to assist in determining the presence of any associated medical conditions or health risk factors and to consider the underlying etiology of their neurobiological disorders.**

ASDs are neurobiologically based conditions that result from changes in brain functioning and have many potential biological causes. The term *etiology* is the medical term that refers to the underlying cause for a medical diagnosis. There are many possible etiologies of ASDs, and a major value of the medical assessment includes the possible identification of a biological explanation for the individual’s ASD.

Etiological associations are best considered risk factors for a range of developmental impairments including ASD. The factors that translate risk factors into the specific developmental phenotype are presently unknown.

Because the diagnosis of an ASD is based on recognition of specific behavioral features, a medical evaluation is not an essential component of the initial diagnostic evaluation. For example, confirmation of the presence or absence of a genetic disorder is not necessary for an experienced clinician to determine whether an ASD diagnosis is warranted. Nonetheless, medical assessment for associated health problems and the underlying cause of the ASD is important.

### Assessment of Sensory and Motor Functioning

**Sensory functioning** refers to an individual’s processing of sensory stimuli in the environment including any unusual interests or negative reactions to specific types of sensory input. **Motor functioning** refers to an individual’s levels of gross and fine motor skills. Gross motor skills involve the larger movements of the arms, legs, feet, or entire body. Fine motor skills include smaller movements of hands, wrists, fingers, lips, and tongue. Assessment of sensory and motor functioning is completed for all individuals diagnosed with ASDs to identify their profile of sensory and motor strengths and concerns.

The lead clinician collaborates with the family to determine if additional sensory and/or motor assessment is needed as part of the clinical assessment for intervention planning.



#### BEST PRACTICE

**Assessment of sensory and motor functioning is completed for all individuals diagnosed with ASDs to facilitate intervention planning.**

process. Specific attention is given to difficulties that interfere with learning and adaptive functioning as well as to any co-existing difficulties relevant to intervention planning. Assessment of sensory functioning includes attention to sensory preferences that may be related to unusual preoccupations or motor stereotypies in addition to sensory aversions. Information about an individual's sensory functioning is particularly relevant to understanding his or her idiosyncratic responses to environmental stimuli and to facilitate planning for intervention.

#### **Assessment of Family Functioning**

**Assessment of family functioning** for intervention planning includes consideration of relevant family variables such as level of parenting stress, impact on siblings and family functioning, extent of family's support network, resources accessed and of interest, financial impact of an ASD diagnosis, and legal considerations. Assessment of the family environment provides a context in which all essential components of assessment for intervention planning are considered to better understand the primary concerns, characteristics, and resources of the family. Family members are typically the primary and constant caregivers in an individual's life. The individual with an ASD influences the family as much as family functioning influences the individual. Issues that stress the family system directly impact the ability to support a family member with a disability. Family assessment facilitates family-centered interventions that strengthen the family's ability to influence the development and well-being of the family member with an ASD.

Adaptation to a child with a disability is a lifelong process that manifests quite differently from family to family and among members within a family. Perception of loss, anger, and/or grief also varies considerably and has little association with the degree of individual impairment associated with an ASD. Cultural values influence family acceptance of the child as well as the family's ability to support intervention. A family's perspective may differ considerably from that of professionals regarding the primary concerns for the individual with an ASD and long-term expectations.

#### BEST PRACTICE

**Assessment of the family environment provides a context in which all essential components of assessment for intervention planning are considered.**

In addition to consideration of the child as part of the larger family system, other family characteristics that existed before, or in spite of, the presence of a family member with an ASD will have a significant impact on the individual's development and adjustment. Parents who lack a support system or financial resources often are overwhelmed by the challenges of caring for an individual with an ASD. Personality patterns and coping strategies in the family also affect family relationships and ability to implement and monitor interventions. The identification of relevant family factors alerts the lead clinician to family needs for specific types of support and influences formulation of recommendations for intervention planning.



# Talking to Parents About Findings

Results of additional assessments are discussed with the family and summarized in a written report. There is significant variability in the process of completing and reporting results from additional assessments depending on whether additional assessments are completed by the lead clinician, by consulting professionals acting independently of each other, or by consulting professionals who are working as part of a multidisciplinary team.

In each case, the lead clinician and any other professionals completing assessments should clarify their current and future role in the individual's care. That role may end when the child is referred to a specific provider for treatment or when the report is sent to parents and the lead clinician. It is important that the family know whom they can contact if difficulties arise in obtaining care, if additional concerns about their child arise, or if they want an update on their child's progress after a period of treatment. Providing families with other resources, such as parent support groups, can also be completed at this time.

Regardless of the number of other professionals involved in the assessment for intervention planning process, the lead clinician collaborates with the family to develop intervention plans and establish treatment providers or ascertains that other consulting professionals have done so in their particular areas of practice. The lead clinician works with the family to obtain informed consent to share findings and intervention plans among relevant professionals and remains available to support care coordination.

When providing feedback to families, professionals recognize that parents may be apprehensive. Therefore professionals consider initiating the discussion by acknowledging the daily challenges a family may be facing and emphasizing that the goal of assessment for intervention planning is to enhance the individual's strengths and address areas of difficulty. In addition, professionals should explain assessment data including test results in understandable terms, translate assessment data into specific targets for intervention, provide practical next steps to begin appropriate services, discuss informed consent, and encourage families to share information across service providers and systems.

## BEST PRACTICE

**The lead clinician and any other professionals completing assessments clarify their current and future roles in the individual's care.**

## BEST PRACTICE

**Professionals talk explicitly with families about their concerns and the potential benefits of sharing relevant information with all service providers involved with the individual with an ASD. The need for parental or individual consent to share information is discussed, and the important role that families can play in facilitating communication among providers is emphasized.**

# Formulation of the Written Report

## BEST PRACTICE

Assessment reports are written in a manner that is accessible and understandable to parents and other service providers and contain practical recommendations for next steps.

## BEST PRACTICE

Following thorough discussion with family members, information about the standardized instruments used and specific test scores obtained are provided as part of the written report, when possible.

Assessment for intervention planning results and recommendations may be included in the diagnostic evaluation report, particularly if the child has had a Tier 3 (e.g., multidisciplinary team) evaluation. In cases where the child is referred to different disciplines for evaluation, there should be a written report for each essential component of assessment for intervention planning.

The written report should be provided directly to the family as well as to the lead clinician who requested the evaluation. Ideally, the various providers evaluating the child will be able to share relevant information, which can help make subsequent assessment more targeted and relevant. For example, if a prior speech and language evaluation has documented a severe language delay, the psychologist will know to choose an appropriate nonverbal cognitive measure.

## COMPONENTS OF A WRITTEN ASSESSMENT REPORT

### Clinical Data

- Description of the referral question and relevant background information
- A summary of any past testing that is relevant to the current assessment
- A description of the assessment process including behavioral observations and any standardized instruments used
- Test results presented in a manner that is understandable to parents and relevant to treating providers
- Discussion of clinical impressions and how assessment results relate to the need for intervention and specific intervention goals

### Next Steps

- Specific recommendations for intervention planning
- A specific plan for follow-up
- Recommended resources

### Community Collaboration

- Clear explanation of the role of the professional providing the assessment and how results may or may not be used in other settings, such as educational or community-based programs
- To the maximum extent possible, the professional(s) involved in the assessment(s) partner with schools and other service providers to document information that may be relevant to eligibility or intervention planning in other settings
- Written assessment reports are comprehensible to parents and social, educational, and other service providers to facilitate enrollment in available services for eligible individuals

# Enhancing Community Collaboration

Clinicians involved in assessment for intervention planning take specific steps to maximize community collaboration, such as clearly discussing the use of assessment results across systems with families, partnering with schools and other service providers to document information that may be relevant to eligibility or intervention planning in other settings, and writing assessment reports in language that is accessible to parents and other service providers.

Individuals with ASDs, their families, and their advocates play an important role in maximizing community collaboration and coordination of care. Partnering with families and involving them at all levels of decision making enhances the family's ability to navigate the multiple service systems involved in planning and delivering intervention services for their child. Families who enter into one service system are informed of the full spectrum of available services so that entry into comprehensive services can occur through any service system and access to the broader spectrum of services can be expedited (Perrin et al., 2007). For example, if assessment for intervention planning is conducted in a medical setting, the lead clinician informs the family of educational or other community-based services that may be available, depending on the child's eligibility, and provides necessary referrals. Similarly, educators inform families about their option to pursue medical services or eligibility evaluation for other services. When assessment results are received from multiple service delivery systems, the family collaborates with professionals in each of the service systems to integrate the various assessment findings into a comprehensive profile of their child's strengths and needs.

Collaboration between clinicians and educators is essential to maximizing coordination of care because individuals with ASDs typically require services from both clinical providers and schools to address their complex strengths and concerns. Clinical assessments can be better tailored to address individual needs and clinical data can more readily be translated into educational planning when collaboration with educators occurs at the beginning of and throughout the assessment process. Intervention planning is enhanced when clinicians and schools partner to synthesize clinical and educational data to inform decision making about intervention goals, environmental accommodations, and behavioral supports. With parental consent, clinicians and educators may consult with one another on an ongoing basis and be invited to attend clinical or educational feedback or planning meetings, as appropriate. It is often helpful to identify a primary contact person in each setting who is responsible for sharing updated information with the family and other providers. In schools, school psychologists or special educators with extensive training and experience specific to ASDs often coordinate educational assessment activities and can play a key role in partnering with clinicians and families to share and synthesize information across settings.

The following Community Collaboration Case Example is provided to illustrate collaboration among families, educational professionals, clinicians, and other service providers to ensure early and accurate diagnosis and comprehensive intervention planning.

# Assessment for Intervention Planning Case Example

## CASE EXAMPLE: COMMUNITY COLLABORATION

### OUTCOMES ENHANCED FROM DIAGNOSIS TO ASSESSMENT FOR INTERVENTION PLANNING

*Ellen is 5 years old. After the first few weeks of school, Ellen's kindergarten teacher became concerned that Ellen was having more difficulty adjusting to school than the other children in her class. Ellen was not able to sit in a chair for more than one minute at a time, screamed and ran away from group activities, seldom spoke to adults or peers, and typically played alone.*

To increase the teacher's ability to help Ellen with classroom routines and participation, the principal agreed to use available staff to assist in the classroom on a rotating basis. The speech-language pathologist and school counselor recommended strategies for increasing Ellen's language and social skills based on observations of Ellen while they were conducting activities with Ellen's class. The teacher agreed to implement and keep track of Ellen's response to these strategies.

The kindergarten teacher also spoke with Ellen's parents to discuss her concerns and the strategies she would be trying. The parents felt Ellen needed more time to adjust because it was the first time she had been in a school environment and were pleased about the initial strategies being implemented. After several weeks, Ellen's parents and educators met to discuss Ellen's response to the strategies and to determine next steps. The school team discussed the kindergarten readiness skills that Ellen needed to progress in the curriculum and a formal process to provide supports in the regular classroom (i.e., Coordinated Early Intervening Services [CEIS]). (For additional information on CEIS, see Appendix J.) The team, including the parents, discussed behaviors that were interfering with Ellen's learning and identified specific strategies to address these concerns. Daily progress monitoring was used to determine the effectiveness of selected interventions, and other modifications were made on an as-needed basis. The team also observed that some of Ellen's behaviors were considered "red flags" for autism spectrum disorders. All agreed that the team would contact Project ACCESS to provide a Missouri Autism Consultant (MAC) to observe in the classroom and make specific recommendations for intervention strategies.

### DIAGNOSTIC EVALUATION PROCESS

At the conclusion of the team meeting, the school counselor explained the differences between an educational evaluation to determine eligibility for special education services and a medical diagnostic evaluation. The potential benefits of a medical evaluation were discussed including the importance of early and accurate diagnosis and how information from a medical evaluation could be used by the school team if a special education evaluation was warranted in the future. The counselor encouraged the parents to speak with their family physician as soon as possible to request an evaluation to determine if a medical diagnosis of an ASD was warranted. The parents gave written consent for information to be shared between the school and the physician.

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The family physician was not experienced with ASDs and referred Ellen to a local psychologist with extensive experience with children with ASDs. As the lead diagnostic clinician, the psychologist collected a thorough developmental history via a background questionnaire, parent interview, and school records provided by Ellen's parents. He observed Ellen and interacted directly with her during a variety of diagnostic activities including administration of the *Autism Diagnostic Observation Scale (ADOS)*. In addition, the psychologist administered a non-verbal cognitive measure, assessed Ellen's basic expressive and receptive language skills, and had the parents and school personnel complete the same standardized rating scales to assess adaptive and overall behavioral functioning across environments.

Based on all evaluation data, the lead clinician concluded that a medical diagnosis of Autistic Disorder was warranted. He discussed the diagnostic conclusions with the parents and answered their questions about the diagnosis and next steps. A copy of the diagnostic evaluation report was provided to the referring family physician. Prior parental consent allowed the psychologist to share and discuss the evaluation report with Ellen's teachers and other appropriate school personnel. The lead clinician provided the family with a copy of the publication *Navigating Autism Services: A Community Guide for Missouri* from the Office of Autism Services and made a referral to the local Regional Office within the Division of Developmental Disabilities, Department of Mental Health (DMH), to determine if Ellen was eligible for DMH services. The clinician also recommended that Ellen receive in-home behavioral therapies and provided the family with a referral to community resources for this service.

### **DETERMINATION OF ELIGIBILITY FOR SPECIAL EDUCATION SERVICES**

After reviewing the medical evaluation report and data from school-based interventions, the school team and Ellen's parents agreed that an evaluation to determine Ellen's eligibility for special education and related services was warranted. The team carefully reviewed the standardized assessments administered as part of the medical diagnosis and identified multiple areas in which additional data would not be needed.

The speech-language pathologist collected additional data needed for intervention planning via parent and teacher ratings of pragmatic language, informal language sample, and informal assessment of Ellen's play skills. Occupational therapy evaluation was completed to identify Ellen's need for classroom accommodations to address any motor or sensory concerns. The district resource specialist conducted a functional behavioral assessment in the kindergarten classroom to address screaming and running away.

When data collection was completed, Ellen's parents attended the eligibility determination meeting and, with their consent, the diagnosing psychologist participated via phone conference. Based on a review of all of the available data, it was

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determined that Ellen's behaviors met the criteria in the Autism eligibility category and that her behaviors adversely affected her educational performance. A meeting was scheduled to develop the Individualized Education Program (IEP). A copy of the Evaluation Summary was sent to Ellen's parents, and parental consent was obtained to send the summary to the family physician, diagnosing psychologist, and the service coordinator at the DMH Regional Office where Ellen's parents had applied for services. (See Appendix I for a listing of Regional Offices in Missouri. Regional Offices are part of the Division of Developmental Disabilities, DMH.)

### **CLINICAL ASSESSMENT FOR INTERVENTION PLANNING**

The diagnosing psychologist agreed to coordinate the clinical assessment for intervention planning process for Ellen and her family. He initially met with Ellen's family to discuss their primary concerns, current access to support and other resources, and family functioning. As the lead clinician, he worked with the family to arrange consultation with a developmental pediatrician who could provide a comprehensive medical evaluation, as well as a behavioral specialist and clinic-based speech-language and occupational therapists to address concerns about communication, sensory functioning, and problem behaviors in home and community settings. Ellen's parents signed releases, shared information, and facilitated communication among the lead clinician, consulting professionals, Ellen's kindergarten teacher and school counselor, and the DMH service coordinator.

### **INTERVENTION PLANNING PROCESS AT SCHOOL**

Ellen's parents and the school-based team of professionals collaborated on the creation of an IEP with input from the diagnosing psychologist and Ellen's DMH service coordinator. Results from the medical evaluation and assessments performed by the school were used to develop a description of Ellen's strengths and concerns, specific goals and related special education services, and needed environmental supports. The team agreed to a schedule for reporting Ellen's progress. Prior written consent from the parents would allow Quarterly IEP Progress Reports to be sent to the lead clinician, the DMH service coordinator, and other relevant service providers.

### **ONGOING COMMUNITY COLLABORATION**

The lead clinician continued to coordinate care for Ellen and her family by maintaining communication with the family physician, educators, therapists, and DMH service coordinator. At a subsequent joint meeting with representatives from the Regional Office and the school, parents expressed a need for additional information about parenting a child with an ASD. The lead clinician helped the family connect with a family support group. All service providers and the parents shared successes with one another in their respective environments to inform consistency of strategies and reinforcements across environments, as applicable. Over time, service providers from the school and the community had a more comprehensive picture of Ellen that allowed them to further individualize interventions to address her unique strengths and concerns across home, school, and community settings.

## SECTION TWO

# Overview of Technical Considerations

This section of the chapter provides a more in-depth discussion of assessment for intervention planning, including overall considerations and specific considerations in each of the seven domains identified as essential components in Section One of the chapter including:

- cognitive and academic functioning;
- adaptive functioning;
- social, emotional, and behavioral functioning;
- communication;
- comprehensive medical examination;
- sensory and motor functioning; and
- family functioning.

### IMPORTANCE OF REVIEWING PRIOR ASSESSMENT DATA

Clinicians conducting assessment of a specific domain of functioning consider the results of prior assessments to inform instrument selection and interpretation of results. Many standardized measures specify time intervals between test administrations that must be accommodated in order to obtain valid test results. Prior assessment results can serve as a baseline for comparison when a clinician is able to re-administer an instrument from which prior results are available. Clinicians consider results from prior assessments to evaluate an individual's pattern of performance over time.

### CONSIDERATION OF FUNCTIONALITY OF SKILLS

Among individuals with ASDs, there is often considerable variability in the ability to demonstrate skills in a controlled clinical setting when compared to real-world applications. Assessment of adaptive functioning provides valuable information about such possible discrepancies. Whenever possible, additional consideration is given to the functionality of the individual's skills by collecting data about the individual's performance on clinical tasks and information about the same skills in home, educational, or community settings.

### ASSESSMENT OF ADOLESCENTS AND ADULTS

Occasionally, assessment is completed with older individuals who have received an initial ASD diagnosis in adolescence or adulthood. This is more likely when symptoms are relatively mild (such as with Asperger's Disorder) or when access to health care is limited. Some individuals, however, may have reached adulthood prior to more widespread awareness of ASDs and remain undiagnosed despite fairly significant symptomatology and otherwise adequate healthcare access. Although many considerations are pertinent to assessment of individuals of all ages with ASDs, assessment of adolescents and adults involves several special considerations.

For adolescents and adults, assessment for intervention planning is guided by a focus on optimal transition planning including the individual's capacity for functional independence particularly in relation to social, residential, and vocational status. Assessment of social functioning includes attention to the individual's level of interpersonal skills and their impact on self-care and employment activities. The individual's relationship history is considered with regard to the individual's desire for and experience of meaningful interpersonal relationships with specific attention to awareness, attitudes, and experiences with romantic or sexual relationships. Social vulnerability and



any experiences of victimization are specifically assessed. In cases in which the individual's capacity for self-care is limited, assessment of family support and care-giving resources are important to determine the need for exploring residential options. Long-term planning is particularly important for individuals with dependence on a family caregiver, such as planning for the individual's care if the caregiver becomes ill or incapacitated. Vocational planning requires consideration of the individual's employment history and assessment of vocational skills and preferences. For higher functioning individuals, neuropsychological testing often aids in educational and vocational planning, particularly when planning for post-secondary education is key to maximizing the individual's outcomes.

In terms of social, emotional, and behavioral functioning, assessment of co-occurring mental health difficulties can become challenging in older individuals who are trying to become increasingly independent and may not be willing to give consent for involvement of family members or other advocates. Medical insurance coverage often becomes a critical issue as individuals age out of eligibility for their parent's coverage. Case management services may be indicated to address access to and continuity of healthcare services. In Missouri, case management or service coordination services are available from state departments, county developmental disability boards, and community mental health centers. Challenging behaviors often become more impairing as individuals age. Assessment for intervention planning includes specific attention to any such behaviors that may limit functional independence even when adequate skills in other domains are present. The need to educate local emergency service providers is specifically discussed because atypical behaviors exhibited by adolescents or adults with ASDs may be alarming to others and prompt involvement with police or other emergency personnel.

# Technical Considerations for Essential Components

## TECHNICAL CONSIDERATIONS FOR ASSESSMENT OF COGNITIVE AND ACADEMIC FUNCTIONING

Assessment of cognitive functioning is completed for all individuals diagnosed with ASDs. The goal of assessment of cognitive functioning is to gain insight into the individual's ability to solve problems, apply and process information, and tolerate structured learning demands, as well as to identify the individual's overall level of functioning and specific cognitive strengths and concerns.

### Assessment of Cognitive Functioning Answers Questions such as:

- What are the individual's overall abilities in comparison to same-age peers?
- Is there a significant discrepancy between the individual's processing of visually based versus verbally based information?
- Is the individual able to generalize information across environments?
- Is there a difference between the individual's concrete versus complex problem-solving skills?
- Does the individual demonstrate poor central coherence or deficits in theory of mind?
- Does the individual use any compensation strategies when approaching tasks?

### Use of Standardized Measures to Assess Cognitive Functioning

The use of standardized instruments to assess cognitive functioning is recommended in order to obtain information about the child's level of cognitive functioning compared to same-age peers. Recent revisions of commonly used cognitive assessment instruments have specifically included individuals with ASDs, as well as other special populations, in their standardization samples, thereby making valid normative comparisons possible.

It is recommended that cognitive evaluation include assessment of both verbal and nonverbal reasoning whenever possible. Individuals with ASDs often exhibit uneven profiles of cognitive skills. Many individuals with deficits in language-based reasoning may exhibit better developed nonverbal skills. In some cases, individuals with ASDs may exhibit the opposite pattern in which some areas of verbal reasoning are better developed than nonverbal skills.

Cognitive evaluation is completed by professionals with training and experience in administration of cognitive tests as well as with specific training and experience assessing individuals with ASDs. Appropriate test selection and modification of testing procedures within the limits of standardization is essential to obtaining accurate estimates of cognitive functioning. Factors to consider in selecting tests include the individual's perceived level of functioning, age, and language proficiency. When cognitive impairment is suspected, specific consideration is given to the floor effects of selected measures so that a lack of or minimal responding does not result in inflated scores. Modifications to testing procedures such as use of a visual schedule of tasks to be completed or use of immediate reinforcers may maximize the individual's engagement in testing without altering the validity of obtained results.

Results of cognitive evaluation are interpreted with caution based on the child's level of engagement, age, severity of core ASD symptoms, or the presence of other behaviors that may confound the results (Kanne, Randolph, & Farmer, 2008). Reporting of cognitive assessment results includes specific statements about the reliability and validity of the information obtained for that particular child. For example, caution is noted when an

### Instruments Used to Assess Cognitive Functioning

- *Leiter International Performance Scale-Revised*
- *Comprehensive Test of Nonverbal Intelligence*
- *Differential Abilities Scale, Second Edition*
- *Bayley Scales of Infant Development, Third Edition*
- *Mullen Scales of Early Learning*
- *Kauffman Assessment Battery for Children, Second Edition*
- *Psychoeducational Profile, Third Edition*
- *Adolescent and Adult Psychoeducational Profile*
- *Stanford-Binet Intelligence Scales, Fifth Edition*
- *Wechsler Preschool and Primary Scale of Intelligence, Third Edition*
- *Wechsler Intelligence Scale for Children, Fourth Edition*
- *Wechsler Adult Intelligence Scale, Fourth Edition*

individual's distractibility, lack of interpersonal engagement, or repetitive behaviors significantly interfere with his or her engagement in testing. Any modifications in standardized test procedures are also noted.

### Special Considerations for Assessment of Cognitive Functioning

**Individuals who are not able to participate in standardized evaluation.** When standardized testing is not possible, other procedures are utilized to obtain information about the individual's level of functioning. Valuable information about an individual's functioning often can be obtained by modifying standardized tasks by testing the limits or modifying instructions. Such modifications are discussed with family members and clearly documented. Standardized interviews or checklists also may be used to collect data about the individual's developmental level via parent interview. Informal observation can strengthen confidence in estimates of functioning based on parent report. Clinicians who utilize observation to supplement other estimates of functional level have extensive training and experience in child development that enables them to identify features of behavior that are often associated with cognitive impairment, such as the individual's level of exploration, complexity of behavior, and rates of stereotypic behaviors.

**Stability of IQ scores.** For all individuals, including individuals with ASDs, IQ scores typically remain stable throughout childhood and adolescence. For very young children, level of cognitive functioning is subject to a certain degree of fluctuation, with the scores stabilizing after 5 years of age. However, IQ scores in individuals with ASDs are often misinterpreted. Instead of representing true capability, low scores are attributed to the child's lack of engagement and high scores on one or more specific tasks are equated with overall level of ability. Cognitive evaluation is completed by experienced professionals to provide assurance that obtained scores provide an accurate estimate of the child's ability. The scores are discussed with parents by professionals who can provide an explanation of test selection, administrative procedures, and interpretation in accessible language along with reassurance about the validity of the results.

**Repeated cognitive evaluation.** When records of previous standardized testing indicate stable cognitive abilities over time, an abbreviated measure (e.g., *Wechsler Abbreviated Scale of Intelligence [WASI]*) may provide sufficient data for assessment for intervention planning purposes.

### Assessment of Academic Functioning

In some cases, academic assessment may be indicated during the clinical assessment for intervention planning process to provide further information about the individual's profile of strengths and concerns; to facilitate identification of co-occurring difficulties; to consider any discrepancies in reasoning, adaptive, and academic skills; or to inform transition planning. Individuals with ASDs may exhibit varied patterns of academic skill development.

### Assessment of Academic Functioning Addresses Questions such as:

- Is the individual making academic progress?
- What is the individual's level of reading skills including decoding, fluency, and comprehension?
- What is the individual's level of mathematics skills including calculation, fluency, reasoning, and problem solving?
- What is the individual's level of writing skills including handwriting, fluency, spelling, and written expression?
- How does the individual function and interact in a classroom environment?
- What accommodations are needed for academic participation?
- What skills does the individual possess that could be used or developed to aid future education and/or employment?

### Instruments Used to Assess Level of Functioning When Standardized Testing Is Not Possible

- Testing of limits or modification of instructions with standardized instruments
- *BRIGANCE Inventories*
- *Developmental Profile-3*
- *Early Learning Accomplishment Profile*
- *Psychoeducational Profile, Third Edition*

### Instruments Used to Assess Academic Functioning

- *Psychoeducational Profile, Third Edition*
- *Woodcock-Johnson Tests of Achievement, Third Edition*
- *Wechsler Individual Achievement Test, Second Edition*

### Assessment of Neuropsychological Functioning

In some cases, neuropsychological assessment may be used to complement and further integrate results of cognitive or academic assessment. Neuropsychological assessment is indicated to (a) address concerns about specific behaviors, such as impulsivity or inattention or specific skills; (b) provide a more comprehensive evaluation of strengths and concerns; (c) establish baseline functioning; and (d) document performance status or changes in performance or when indications of neurological involvement impacting specific systems are present (Corbett, Carmean, & Fein, 2009; Kanne et al., 2008). The extent of the neuropsychological assessment and instruments used depends on the specific questions or concerns to be addressed. Relevant areas of neuropsychological assessment may include cognitive functioning, adaptive skills, attention, sensory processing, motor ability, language, visual-spatial and visual-motor ability, executive functioning, learning and memory, academic skills, and social-emotional functioning.

### Neuropsychological Assessment Addresses Specific Questions such as:

- Does the individual take longer to complete tasks due to slow processing speed?
- Are there difficulties with the individual's memory? Is the individual able to encode, store, and retrieve both verbal and nonverbal information in an efficient manner?
- Is there evidence of difficulties with attention?
- Does the individual exhibit any difficulties with executive functioning?
- Is there clinical evidence of a specific pattern of neurological concerns?

### TECHNICAL CONSIDERATIONS FOR ASSESSMENT OF ADAPTIVE FUNCTIONING

Assessment of adaptive functioning is completed for all individuals diagnosed with ASDs regardless of cognitive or developmental level. Understanding the individual's typical functioning across settings facilitates identification of areas in need of intervention and specific strengths that can be utilized as a foundation for intervention strategies.

### Assessment of Adaptive Functioning Addresses Questions such as:

- Does the individual independently complete daily activities related to feeding, dressing, toileting, and personal hygiene?
- At what level does the individual engage in home living activities such as preparing food and completing chores?
- What is the individual's level of community skills such as using appropriate transportation, managing money and time, navigating community services, and engaging in self-advocacy?
- Does the individual exercise appropriate safety?
- How well does the individual perform the skills needed in the next home, school, or community setting with which he or she will be involved?
- How well does the individual's current living, educational, or employment environment fit with his or her needs?
- What support services are needed to plan for any foreseeable transitions from one classroom, program, or service delivery system to another?

The majority of standardized adaptive behavior scales rely on third-party reporting of the individual's behavior. Although parents typically are the most reliable source of information about an individual's behaviors, there may be difficulties with reporting about the individual's typical behavior including language or cultural barriers, lack of opportunity to observe certain behaviors, or difficulty with recall. Teachers and childcare providers provide important insight about the child's typical functioning in an educational setting but may have limited information about the child's functioning in other settings. Therefore, assessment of adaptive functioning includes information from as many sources as possible. Whenever possible, information is obtained both from parents and from others familiar with the child such as childcare providers or educators because an individual's functioning can vary widely across settings.

### Instruments Used to Assess Adaptive Functioning

- *Vineland Adaptive Behavior Scales, Second Edition*
- *Adaptive Behavior Assessment System, Second Edition*
- *Scales of Independent Behavior, Revised*

Assessment of adaptive functioning considers whether an individual is able to perform a skill independently or what level of support is required for successful completion of a specific task. Data about an individual's functioning across multiple settings provides valuable information about skill generalization and environmental variables that may facilitate or limit independent functioning. Expectations for functional independence take into account the individual's age and developmental level. When areas of difficulty are identified, attention is given to whether the individual has developed the foundational skills required for successful completion of a more complex skill.

### **Emphasis on Successful Life Transitions**

Assessment of adaptive functioning places specific emphasis on the skills needed for successful life transitions. For school-age children, attention is given to transitions between school programs and settings. For adolescents, the emphasis is on post-secondary transitions to educational or vocational programs, employment, and supported or independent living. An awareness of transition issues helps to direct assessment for intervention planning toward assessment of skills needed for later success.

Clinicians may utilize informal clinical interview procedures to solicit information about social and emotional functioning based on their own clinical experience and training. Structured psychiatric interviews may be used as a guide provided that careful consideration is given to differentiation of symptoms commonly found in ASDs. Rating scales completed by parents or others familiar with the child also can provide useful information; again, results must be interpreted in the context of the individual's ASD diagnosis. Similarly, self-report measures can provide valuable data but must be interpreted in light of potential deficits in social understanding and self-awareness commonly associated with ASDs.

## **TECHNICAL CONSIDERATIONS FOR ASSESSMENT OF SOCIAL, EMOTIONAL, AND BEHAVIORAL FUNCTIONING**

Comprehensive assessment of social, emotional, and behavioral functioning is completed for all individuals diagnosed with an ASD to facilitate intervention planning.

### **Assessment of Social, Emotional, and Behavioral Functioning Considers Questions such as:**

#### **SOCIAL**

- Does the individual
  - show awareness of or interest in others?
  - initiate social interaction with or without prompting?
  - interact differently with younger individuals, peers, and adults?
  - wait to take turns?
  - engage in planning of social activities?
  - display emotions that are an appropriate match for the social environment?
- How does the individual
  - respond to others?
  - seek attention or request help?
  - interact with others one-on-one? in a small group? large group?

#### **EMOTIONAL**

- Does the individual exhibit co-occurring symptoms such as obsessions or compulsions, depression, or anxiety that interfere with daily functioning?
- How does the individual cope with difficulties?
- What is the individual's level of self-awareness and self-advocacy skills?

#### **BEHAVIORAL**

- What behaviors interfere with or enhance the individual's functioning in home, school, or community settings? What is the specific nature of these behaviors such as frequency, intensity, and duration?

- Does the individual attempt to or engage in behaviors that:
  - are harmful to self or others?
  - disrupt others or damage property?
  - are socially problematic or offensive?
- Does the individual
  - withdraw from others or from specific situations?
  - attend when required?
  - follow rules when required?
- What does the individual find motivating?
- What environmental variables seem to contribute to problem behaviors or facilitate more adaptive behaviors?

PROCEDURES COMMONLY USED FOR ASSESSING CHALLENGING BEHAVIORS

TABLE 4.2

<b>POSITIVE BEHAVIORAL SUPPORTS</b>	A process for understanding challenging behaviors and developing a plan that promotes development of new skills while reducing the child's need to engage in adverse behaviors (Carr et al., 2002)
<b>FUNCTIONAL ANALYSIS OF BEHAVIOR</b>	A process used to understand how an individual with challenging behaviors functions successfully within their environment; focuses on analysis of antecedents of events that predict behavior, a concrete description of the behavior, and the consequences that maintain the behavior (Hanley et al., 2003)

#### Instruments Used to Assess Social, Emotional, and Behavioral Functioning

- Informal Symptom Interviews
- Structured Interviews:
  - *Diagnostic Interview Schedule for Children (DISC)*
  - *Autism Comorbidity Interview-Present and Lifetime Versions*
- Behavior Rating Scales
  - *Behavior Assessment System for Children, Second Edition (BASC-2)*
  - *Achenbach Scales (e.g. Child Behavior Checklist; CBCL)*

### TECHNICAL CONSIDERATIONS FOR ASSESSMENT OF COMMUNICATION

Comprehensive assessment of communication skills is completed for all individuals diagnosed with ASDs to facilitate intervention planning. Whenever possible, communication assessment includes one-on-one testing with standardized instruments, informal communication sampling, and skill ratings from parents and others familiar with the child. Information from multiple sources is particularly valuable for more severely impaired children who may demonstrate a higher level of skill in familiar settings, as well as for cognitively able individuals who may be able to perform well on discrete clinical tasks but struggle with daily application of higher level language skills.

#### Assessment of Communication Addresses Questions such as:

- What is the individual's preferred mode of communication?
- What is the individual's ability to comprehend spoken language?
- Is the individual able to understand auditory inputs when there are no visual cues?
- Does the individual exhibit idiosyncratic speech patterns?
- What is the individual's level of expressive language?
- Can unfamiliar listeners understand the individual when he or she is speaking?
- Does the individual attend to paralinguistic cues such as tone of voice, rate of speech, and facial expressions?
- Can the individual appropriately use communication skills to make requests and for a variety of other functions in various settings?
- Can the individual appropriately initiate, sustain, and conclude reciprocal interaction patterns?
- Does the individual understand and use abstract language skills such as nonliteral language and other aspects of pragmatic language?
- Is the individual able to retrieve and organize language without prompting?

#### Instruments Used in Communication Assessment

- *Autism Diagnostic Observation Schedule*
- *Expressive and Receptive One-Word Picture Vocabulary Tests, Second Edition*
- *Psychoeducational Profile, Third Edition*
- *The Functional Communication Profile*
- *Goldman-Fristoe Test of Articulation, Second Edition*



A total communication approach is utilized in describing communication abilities in individuals with ASDs including assessment of nonverbal and preverbal precursors to language development such as communicative intent and use of eye gaze, gesture, and vocalization. It is important to evaluate the differences in understanding and/or use of language across contexts and communication partners as well as the functionality of communication overtures. In individuals with some verbal ability, it is important to examine more domain-specific abilities such as receptive and expressive skills as well as pragmatic use and understanding.

#### **Instruments Used in Assessment of Communication for Very Young Children with ASDs**

- *Clinical Evaluation of Language Fundamentals-Preschool including Pragmatics Profile*
- *Preschool Language Scale, Fourth Edition*
- *Peabody Picture Vocabulary Test, Fourth Edition*
- *MacArthur-Bates Communicative Development Inventories, Third Edition*
- *Reynell Developmental Language Scales-III*
- *Sequenced Inventory of Communicative Development-Revised*
- *Test of Early Language Development*
- *Test of Language Development-Primary*

#### **Assessing Communication in Very Young Children**

Communication assessment of very young children requires attention to many subtle behaviors and careful observation of the presentation and quality of various aspects of communication including the “frequency of communicative attempts, the functions of these attempts, the means used to accomplish communication goals, and the level of responsiveness to others’ communicative attempts” (Paul & Wilson, 2009, p. 173). Diagnostic evaluation at any tier provides information about at least some of these aspects of communication in young children diagnosed with ASDs as they are central to diagnosis. However, further informal or standardized communication assessment may be indicated to inform intervention planning. Standardized instruments include instruments administered during one-on-one testing by a trained examiner. Informal assessment via observation and interaction with the child supplemented by parent interview data is indicated in cases where the child is not able to participate in standardized testing.

#### **Assessing Communication in Nonverbal Individuals**

Research indicates that a significant number of individuals with ASDs remain nonverbal despite intervention efforts. For nonverbal individuals, attention is given to preverbal and nonverbal communication. In addition, assessment for intervention planning attends to the individual’s need for augmentative and alternative communication and provides information that facilitates identification of the most appropriate communication system for the individual. Relevant domains include the individual’s level of cognitive and linguistic development, receptive language, and literacy skills. Consideration is given to use of aided or unaided systems or a combination of both.

For individuals who are nonverbal, norm-referenced measures that provide information about functioning compared to same-age peers are often of little utility in assessment for intervention planning. Instead, criterion-referenced tools, observation, and reports from parents and others familiar with the individual typically are most instructive.

#### **Instruments Used in Assessment of Communication in Individuals with ASDs Who Are Nonverbal**

- *Augmentative Communication Assessment Profile*
- *Matching Assistive Technology and Child*
- *Developmental Assessment for Individuals with Severe Disabilities, Second Edition*
- *Picture Exchange*



### Assessing Communication in Individuals Who Are Verbally Fluent

Comprehensive communication assessment remains an important aspect of assessment for intervention planning even for verbally fluent individuals. Attention is given to expressive and receptive language skills as well as to language-related cognitive domains. Particular emphasis is placed on assessment of social communication or pragmatic language including skills such as functional use of language, organizing turns and topics in conversation, and adjusting language usage to the context. Collecting information from multiple sources is particularly important in the assessment of pragmatic language because cognitively able individuals may be able to reason out responses to isolated clinical tasks, yet still struggle with real-world social communication.

### TECHNICAL CONSIDERATIONS FOR COMPREHENSIVE MEDICAL EXAMINATION

ASDs are diagnosed by medical as well as mental health and other health professionals. When the ASD diagnosis is made by a physician, the medical assessment can be completed during the diagnostic phase. Physicians typically diagnose ASDs and assess for biological causes and/or associated medical concerns during a single evaluation. When the diagnosis of an ASD is made by a non-physician, a comprehensive medical evaluation occurs during the assessment phase.

#### The Comprehensive Medical Examination Addresses One Key Question:

- Does the individual exhibit medical signs that indicate associated medical conditions or a specific etiology underlying his or her impairments?

The medical assessment includes the following: a review of medical records to be certain that appropriate vision and hearing testing has been performed, a standard medical history, a physical examination with an assessment for dysmorphology (i.e., atypical physical features of facial or body structures indicative of abnormal processes occurring during embryogenesis), and a neurodevelopmental examination. The medical assessment focuses on two separate issues:

1. the presence of medical conditions that require additional medical evaluation or therapy, and
2. the possible cause or etiology of the ASD itself.

There are several potential benefits to approaching the medical examination in this way. The approach can assist in the selection of medical therapies as well as in the identification of an underlying etiology that may direct the therapeutic plan and inform recurrence risk assessment.

#### Instruments Used in Assessment of Communication for Verbally Fluent Individuals with ASDs

- *Clinical Evaluation of Language Fundamentals, Fourth Edition including Pragmatics Profile*
- *Test of Language Competence*
- *Comprehensive Assessment of Spoken Language*
- *Test of Pragmatic Language*
- *Children's Communication Checklist-2*
- *The Pragmatic Rating Scale*
- *Oral and Written Language Scales*
- *Test of Problem Solving-Elementary, Third Edition*
- *Test of Problem Solving-Adolescent, Second Edition*

### Comprehensive Health History

During the diagnostic evaluation process, the amount of health history obtained and whether it is reviewed by a physician varies case-by-case based upon the type of professionals involved in a particular diagnostic evaluation. In cases where a comprehensive health history has not been reviewed by a physician as part of the diagnostic evaluation process, such a review should occur as part of assessment for intervention planning.

A detailed health history includes prenatal and perinatal history, past medical history of the individual, three-generation family health history, and detailed review of systems. This information can be obtained by a physician or another healthcare professional with adequate training and experience in conducting health history interviews. Healthcare professionals often are able to obtain this information with provision of basic guidelines, but the information obtained should be reviewed by a physician. Information obtained from health history questionnaires is clarified by an in-person interview.

A comprehensive health history includes:

- **The current chief complaint and a focused interview** regarding acquisition of developmental milestones in all domains, the presence or absence of developmental and/or speech regression, and current medical health status.
- **Prenatal history** including information about maternal age and health, the specifics of the pregnancy, and any variations from normal including injury or illness, medication therapy, or pregnancy complications requiring procedures or therapy.
- **Perinatal history** including information about length of gestation, onset of labor, and any complications during labor or delivery; birth weight, length, and head circumference; Apgar scores and any need for post-delivery resuscitation; and documentation of neonatal course including any neonatal illnesses or complications.
- **Past medical history** such as medication history, hospitalizations, surgeries, illnesses, and injuries. Specific questions are asked about:
  - developmental milestones and acquisition of skills: presence or absence of developmental regression;
  - known neurological disorders, such as seizures;
  - head injuries associated with loss of consciousness;
  - documentation of infectious diseases and immunization status;
  - dietary and nutritional information; and
  - known allergies.
- **Family medical history** with a three-generation pedigree and particular attention to:
  - the presence of other family members with ASDs;
  - other developmental, learning, or psychological difficulties;
  - degenerative neurological disorders.
- **Review of systems as follows:**
  - all medical organ systems are explored for possible symptoms of underlying or co-occurring medical disorders;
  - specific attention to sleep concerns including difficulties with sleep onset, night awakening, and parasomnias;
  - specific attention to gastrointestinal concerns such as diarrhea or constipation.

## Assessment for Associated Medical Conditions

- Vision and Hearing Impairments
- Sleep Disorders
- Gastrointestinal Conditions
- Nutritional Deficiencies
- Seizures

Individuals with ASDs are subject to the same health risks, physical illnesses, and injuries as others, and on-going health care with appropriate medical monitoring and treatment for such conditions is best provided by a PCP within a Medical Home model. The physician should consider general health issues such as diet, growth, immunizations, and other aspects of general health maintenance appropriate to the person's age during the medical assessment. In addition, there are a number of specific medical conditions that occur more frequently in those with ASDs and require special consideration. These include lead ingestion secondary to pica and obesity. Other frequent associations include vision and hearing impairments, sleep dysfunction, gastrointestinal complaints, nutritional deficiencies, and seizures.

### VISION AND HEARING IMPAIRMENTS

Vision and hearing impairments can occur in association with any developmental disability, and the individual's vision and hearing status should be determined as part of the medical assessment. If hearing and vision have been tested previously, this can be confirmed by obtaining the reports; if not tested, their evaluation should be considered a component of the medical assessment. Behavioral audiometric testing by an experienced audiologist and vision screening by a developmental or medical professional are adequate in the majority of cases. When situations arise in which the visual and hearing status of a young child or poorly cooperative individual cannot be determined, additional measures such as sedated brainstem evoked potential testing or referral to vision professionals with special expertise may be required. Consultation with an ophthalmologist is recommended for those with strabismus or uncertain visual status and can also be an important component of the etiological assessment for some individuals. Confirmation of the individual's vision and hearing abilities is an important component of the medical assessment.

### SLEEP DISORDERS

Sleep disruption is common in persons with ASDs. Parental sleep diaries and questionnaires document insomnia with prolonged time to fall asleep, decreased sleep duration, and increased awakenings in approximately 50% of children with ASDs (Malow & Magrew, 2006; Wiggs & Stores, 2004; Williams, Sears, & Allard, 2004). Sleep difficulties have multiple causes including obstructive sleep apnea, circadian rhythm abnormalities, anxiety disorders, nocturnal seizures, medication side effects, and associated temperamental and behavioral factors including hypersensitivity to environmental stimuli. The physician should obtain information regarding the child's sleep hygiene and provide guidance when indicated. Depending on the severity of any sleep disturbance and its clinical features, the physician can determine the need for additional behavioral assessment, further medical testing with overnight polysomnography, and/or a consultation with a sleep disorder specialist.

#### GASTROINTESTINAL CONDITIONS

Gastrointestinal (GI) and feeding problems have also been described in studies of children with ASDs and are frequent concerns of parents of affected children (Horvath et al., 2000). Whether the prevalence of GI complaints, including constipation and diarrhea, can be explained by the neurobehavioral variations and feeding issues due to ASDs themselves or are related to associated gastrointestinal pathology is still under investigation (Coury et al., 2009; Ibrahim et al., 2009). Noting the potential for GI disorders to contribute to problem behaviors in those with ASDs, a recent consensus report recommended the integration of behavioral and medical care to optimize the diagnostic and management approaches (Buie et al., 2010).

The physician also needs to consider the individual's dietary history and food preferences or aversions that might contribute to obesity or inadequate nutritional status. In addition, it is important to inquire about bowel habits and any symptoms of abdominal discomfort that may impact the individual's health status. Chronic constipation is particularly frequent, and abdominal discomfort and gastroesophageal reflux are possible contributors to episodic or chronic behavioral difficulties in those with ASDs. Radiographic studies and/or consultation with a gastroenterologist familiar with ASDs should be obtained when medically indicated.

#### NUTRITIONAL DEFICIENCIES

Nutritional risk factors occur commonly in children with ASD. These include limited food preferences, deficiencies of specific nutrients secondary to popular dietary treatments (i.e., gluten and casein-free diets), and medication effects. At the other extreme, obsessive eating and medication side effects may also contribute to obesity. Ongoing monitoring of growth and nutritional status is recommended with referral to a registered dietician when there are nutritional concerns.

#### SEIZURES

Seizures are relatively common in individuals with ASD. Seizures are caused by abnormal cerebral electrical activity that varies in type and duration. Although they can occur at any age, seizures typically begin before 5 years of age or after puberty in persons with ASDs. The prevalence of seizures increases with age and the severity of associated cognitive and motor impairments (Tuchman & Rapin, 2002). In general, seizures should be evaluated and treated by neurologists.

#### EPILEPSY

Epilepsy is the medical term for recurrent seizures. The diagnosis of epilepsy is based on a history of recurrent episodes of altered consciousness and/or abnormal motor activity suggestive of clinical seizures and is usually confirmed by associated abnormalities on an electroencephalogram (EEG). The EEG uses scalp electrodes to record brain electrical activity and can identify patterns known to be associated with epilepsy, termed "epileptiform." Generally, epileptiform EEG activity has no direct impact on brain functioning, but in rare situations extremely frequent epileptiform activity in young children can disrupt normal brain function and produce regression of developmental skills (Roulet-Perez & Deonna, 2006). This rare condition termed "epileptic encephalopathy" occurs only in children and can be diagnosed and treated by child neurologists.

#### LANDAU-KLEFFNER SYNDROME (LKS)

Landau-Kleffner syndrome (LKS) is the most relevant epileptic encephalopathy with respect to ASDs because this rare disorder produces loss of receptive and expressive language skills between 3 and 8 years of age. The language regression in LKS is similar to the developmental regression identified in approximately one-third of children with ASDs but typically occurs in somewhat older children and is always associated with severely epileptiform EEGs (Mantovani, 2000). Children who experience isolated language regression *after* 24 months of age or global developmental regression after the age of 3 years should have a consultation with a child neurologist and consideration of a sleep EEG, including an overnight study in some situations (Mantovani, 2008).

#### Assessment for Etiological Conditions

A major value of and focus for the medical assessment is the possibility of identifying a biological explanation for the individual's ASD. ASDs are neurobiologically based conditions that result from changes in brain functioning and have many potential biological causes. ASDs can occur in isolation or as part of a recognizable medical condition. Twin and family studies have established the preponderant genetic basis of ASDs and indicate that the heritability of autism is over 90%. Even so, a specific genetic cause can be identified in only 20% to 25% of children with autism at the present time (Miles et al., 2010; Monaco & Bailey, 2001). In a small number of cases, the cause of ASD can be traced to a specific teratogenic exposure, in-born metabolic disorder, or structural brain abnormality. The cause of ASDs in the remaining majority remains unknown.

Given the wide spectrum of physical, intellectual, and behavioral manifestations of ASDs, it is not surprising that there are many etiologies. In many cases, the presumed etiology for ASD is based on the association of historical or pathophysiological risk factors.

It is unclear at this time whether there is any etiological significance to the current *DSM-IV-TR* distinctions among the various ASDs (i.e., the extent to which etiological testing should differ for those with the more severe manifestations from the more numerous children who fall within the broader ASD phenotype). On-going prospective studies should lead to more definitive recommendations for etiological testing in the near future. Recent reports from the American Academy of Pediatrics (Johnson & Myers, 2007) and the American College of Medical Genetics (Schaefer & Mendelsohn, 2008) provide practical approaches to the evaluation of children with ASDs and an approach to etiological testing based on the patient history and examination. Medical conditions with a potential for an etiological association with ASDs are listed in Table 4.3.

**MEDICAL DIAGNOSES ETIOLOGICALLY ASSOCIATED WITH ASDs**

TABLE 4.3

<p><b>GENETIC/CHROMOSOMAL DISORDERS</b> (20–30%)</p>	<ul style="list-style-type: none"> <li>■ Single gene disorders (~5%)                             <ul style="list-style-type: none"> <li>– Fragile X syndrome</li> <li>– Tuberous sclerosis complex</li> <li>– Neurofibromatosis</li> <li>– PTEN macrocephaly syndrome</li> <li>– Timothy syndrome</li> <li>– Joubert syndrome</li> </ul> </li> <li>■ Cytogenetically visible chromosome disorders (~5%)                             <ul style="list-style-type: none"> <li>– Maternally derived duplication of 15q11-q13 region (Prader-Willi/Angelman syndrome critical region)</li> <li>– Trisomy 21</li> <li>– Turner syndrome</li> <li>– Other</li> </ul> </li> <li>■ Copy number variants (CNV) (10–20%)                             <ul style="list-style-type: none"> <li>– 16p11.2 deletion syndrome</li> <li>– 15q13.3 syndrome</li> <li>– Other</li> </ul> </li> </ul>
<p><b>METABOLIC DISORDERS</b> (1–3%)</p>	<ul style="list-style-type: none"> <li>■ Phenylketonuria (untreated)</li> <li>■ Mitochondrial disorders</li> <li>■ Creatine transporter &amp; biosynthesis disorders</li> <li>■ Smith-Lemli-Opitz syndrome</li> </ul>
<p><b>OTHER DISORDERS</b> (very small but unknown percentage)</p>	<ul style="list-style-type: none"> <li>■ Fetal toxin/drug exposure (misoprostol, valproic acid, thalidomide)</li> <li>■ Structural brain abnormality from injury, malformation, or prenatal infection</li> <li>■ Moebius syndrome/sequence</li> <li>■ Epileptic encephalopathy (infantile spasms, Landau-Kleffner syndrome)</li> </ul>

Although these etiological diagnoses are associated with the developmental phenotype of ASDs, their associations are variable. For example, most individuals with neurofibromatosis, Down syndrome, and in utero valproic acid exposure do not have ASDs, whereas most individuals with fragile X syndrome or several of the copy number variant disorders meet the criteria for ASDs. As a result, these etiological associations are best considered as risk factors for a range of developmental impairments including ASDs. The factors that translate the biological risk factors into the specific developmental phenotype are presently unknown.

At this time, there is no single answer to how much medical testing of which types are needed for each person diagnosed with an ASD. The physician involved in the medical assessment process must use an individualized approach. In general, the physician's priorities are to identify the few conditions that have direct biological therapies and to diagnose the larger number with either important genetic implications or explanatory neuroimaging findings.

Etiological diagnoses can be based on the medical history, examination, or medical testing.

### Etiology from History

Risk factors for ASDs include a past history of maternal use of medications such as valproic acid, misoprostol, and thalidomide during pregnancy, fetal growth restriction, premature birth and/or neonatal encephalopathy (Badawi et al., 2006; Kolevzon, Gross, & Reichenberg, 2007). Prenatal viral infections, especially fetal rubella, have been noted in the past but are now considered unlikely causes. The correlation of risk factors with associated clinical findings, laboratory studies, or brain MRI results can be used in the attempt to establish a causal relationship of such factors to the presence of an ASD.

Although Rett syndrome (RS) is listed as a PDD, it has now been shown to be a clinically distinct genetic condition that has some phenotypic overlap with idiopathic autism. Early symptoms of RS such as language loss and reduced hand use may initially suggest an ASD, but RS can be distinguished by decreasing rate of head growth, hand wringing stereotypies, and a progressive gait disturbance. Such findings in girls should prompt genetic testing for MECP2 mutations.

Genetic influences will also be apparent from the history in some individuals. A three-generation pedigree should be obtained with attention to developmental, psychiatric, and neurologic diagnoses. A family history of ASDs or related symptoms in a sibling or family member supports an underlying genetic mechanism and should prompt referral to a geneticist for further evaluation.

Metabolic disorders are suggested by a history of failure to thrive, hypotonia, episodic illnesses, developmental regressions, fatigue, metabolic acidosis, and/or associated neurological symptoms.

### Etiology From Examination

#### PHYSICAL AND DYSMORPHOLOGY EXAMINATIONS

Measurement of height, weight, and head circumference can identify microcephaly or growth retardation, which suggest various chromosome and monogenic syndromes. A head circumference well above the 98%tile or below the 2%tile for age is a significant finding on examination that may indicate the need for additional testing. Although macrocephaly is a common feature in ASDs (~35% of children), its presence should prompt consideration of disorders such as fragile X syndrome and PTEN macrocephaly syndrome. Brain MRI can also help to identify the etiology in some of these cases, although findings are often non-specific (Battaglia & Carey, 2006).

Children with generalized dysmorphism (i.e., atypical physical features that date the onset of the condition to early embryogenesis), small stature (<10th %tile), or major birth defects should be evaluated by a medical geneticist for a possible syndromic diagnosis or cytogenetic abnormality (Herman et al., 2007; Miles et al., 2008).

A detailed examination of the skin is also recommended including Wood's lamp examination for evidence of tuberous sclerosis complex and neurofibromatosis-Type 1.

#### NEURODEVELOPMENTAL EXAMINATION

Associated findings of cognitive and motor impairments are important factors in considering the potential value of etiological testing. In general, the greater the degree of cognitive impairment and the more prominent the motor impairments, the higher the probability of an etiological diagnosis in children with developmental delays (Cass, Sekaren, & Baird, 2006; Shevell, 2009).

Although it is common for individuals with ASDs to have mild hypotonia and poor motor planning, more severe hypotonia and motor dysfunction can be associated with underlying genetic disorders that can be identified by genetic laboratory testing. Those



who have other types of motor dysfunction such as focal or lateralizing motor deficits may have structural abnormalities that can be recognized with neuroimaging. Individuals with spasticity, impaired motor control, or involuntary movements may also have cerebral palsy (a syndrome of non-progressive hypertonic, dyskinetic, or ataxic motor impairments beginning in the first years of life), which can be recognized on examination. Cerebral palsy is often associated with patterns of brain injury on magnetic resonance imaging (MRI), which indicate the mechanism and timing of brain injury and may serve to identify the etiology of the ASD.

### **Etiology from Testing**

Medical testing identifies genetic, metabolic, and structural brain-based etiologies based on abnormalities on genetic or biochemical laboratory testing or on neuroimaging studies such as MRI.

#### **GENETIC TESTING**

Children with ASDs and major cognitive impairment, particularly in association with dysmorphic facial or body features, should be considered for genetics consultation and laboratory studies. Array comparative genomic hybridization (aCGH) is replacing high-resolution chromosome analysis and FISH in the evaluation of children with autism. DNA for fragile X syndrome is recommended to identify the 1%-3% of children with ASDs due to fragile X syndrome and also to detect pre-mutation status, which appears to be an ASD risk factor (Loesch et al., 2007). Depending on the clinical history and examination findings, other specific tests such as MECP2 gene testing for Rett syndrome, methylation analysis for Angelman syndrome, PTEN gene testing, 7-dehydrocholesterol level for Smith-Lemli-Opitz syndrome or others will be indicated (Miles et al., 2010).

#### **NEUROIMAGING**

As noted above, children with ASDs and major cognitive impairment (IQ or developmental quotient less than 50% of expected), significant microcephaly or macrocephaly, associated cerebral palsy, or a history suggestive of in utero or neonatal neurological dysfunction should be considered for neuroimaging. Brain MRI is the preferred study in view of its lack of radiation exposure and its increased sensitivity for identification of structural abnormalities. However, the risks of anesthesia that may be required to obtain the MRI must also be considered. The results of the MRI may suggest the need for further genetic or neurometabolic testings, and abnormalities usually indicate the need for further consultations with a neurologist or geneticist.

#### **METABOLIC TESTING**

Although comprehensive newborn metabolic screening as performed in Missouri will identify many congenital metabolic conditions, children with ASD should be considered for additional neurometabolic testing if there is a history of episodic illness with regressions, metabolic acidosis, ataxia, seizures, or muscle weakness. This testing should also include consideration of mitochondrial disorders if there is associated growth retardation (<2%tile for weight and/or height), hypotonia, delayed motor milestones, multiple episodes of regression, unusual fatigability and exercise intolerance, deafness, oculomotor abnormalities, or other unexplained body organ dysfunction (Weissman et al., 2008). Such symptoms indicate the need for specialty consultation with a geneticist or neurologist, particularly since individuals with ASDs due to biochemical disorders have the most potential to benefit from biological therapy in addition to a need for genetic counseling.

## TECHNICAL CONSIDERATIONS FOR ASSESSMENT OF SENSORY AND MOTOR FUNCTIONING

### Sensory Functioning

Differences in sensory processing are commonly reported in individuals with ASDs including over- and under-reaction to sensory input. As a result, individuals with ASDs may exhibit behaviors that are characterized as sensory seeking or avoidant. Assessment of sensory functioning includes attention to both sensory preferences and aversions. Examples of unusual sensory interests include intense focus on specific visual stimuli such as moving parts of objects or lights. Sensory aversions may include oral aversions and tactile and/or auditory defensiveness. Specific consideration is given to the extent to which the individual's sensory processing is atypical in its content, frequency, or intensity compared to other individuals at the same developmental level, as well as whether the sensory preferences or aversions result in functional impairment. Attention is given to the interaction between sensory differences and motor functioning, as apparent motor difficulties such as an unusual gait may be impacted by sensory preferences or aversions.

#### Assessment of Sensory Functioning Addresses Questions such as:

- Does the individual under- or over-react to typical sensory information from the environment?
- Is the individual's activity level appropriate to environmental demands?
- Are there sensory-seeking or defensive behaviors that interfere with daily functioning in home, school, or community settings?

### Motor Functioning

Individuals with ASDs may present with a range of difficulties in fine and/or gross motor functioning. Although these motor difficulties may not be ASD-specific, they often have a significant impact on the individual's adaptive functioning. Age appropriate achievement of early motor milestones such as walking independently should not be over-generalized as an indication that no motor difficulties are present.

#### Assessment of Motor Functioning Addresses Questions such as:

- Are gross and/or fine motor difficulties related to muscular weakness, sensory processing, or motor planning issues?
- Are gross and/or fine motor difficulties interfering with the individual's ability to participate in activities of daily living in the home, school, and/or community?
- Are fine motor difficulties leading to non-adaptive ways of playing or performing other activities because of inability to use hands functionally?
- Is there evidence of oral motor difficulties associated with mouthing objects, decreased tolerance of foods, limited oral exploration, excessive drooling, poor speech intelligibility, and/or choking or gagging?

Assessment of motor functioning considers both reports from parents and reports from others familiar with the child along with direct assessment of the individual. Areas that may be assessed include fine motor speed and dexterity, visual-motor skills, oral motor skills, and gross motor skills such as gait, agility, strength, balance, and bilateral coordination.

#### Instruments Used to Assess Sensory Functioning

- *Sensory Profile*
- *Toddler Sensory Profile*

#### Instruments Used to Assess Motor Functioning

- *Beery-Buktenica Developmental Test of Visual-Motor Integration*
- *Peabody Developmental Motor Scales, Second Edition*
- *Bruininks-Oseretsky Test of Motor Proficiency, Second Edition*
- *Pediatric Evaluation of Disability Inventory*
- *Test of Visual Perceptual Skills, Third Edition*

## TECHNICAL CONSIDERATIONS FOR ASSESSMENT OF FAMILY FUNCTIONING

Family assessment facilitates family-centered interventions that strengthen the family's ability to influence the development and well-being of the family member with an ASD. Attention is given to existing family assets and resources that enhance the family's ability to support the individual with an ASD and to cope with associated challenges. Likewise, stressors, concerns, or unmet needs that may limit family support and coping are considered. Some assets and stressors may be ASD-specific, such as the family's level of understanding of ASDs and access to ASD-specific resources. Other assets and stressors may be more general, yet equally important, such as relationships with others who can provide emotional and practical support or the extent to which the family's basic needs are being met.

Family members are interviewed about their primary concerns and expectations as they may differ significantly from those of the professionals involved with the family. Attention is given to the family's values and coping strategies and the personality of family members. The identification of relevant family factors alerts the lead clinician to family needs for specific types of support and influences formulation of recommendations for intervention planning. For example, some families may respond positively to being provided with multiple written resources such as books, magazine articles, or websites, while the same amount of information may seem overwhelming to other families.

### Assessment of Family Functioning Addresses Questions such as:

- What are the family's current assets that facilitate effective family functioning, coping, and support of the family member with an ASD?
- What are the family's values, concerns, and expectations for the individual with an ASD?
- What is the level of parenting stress related to the child's diagnosis or other issues?
- How have siblings and overall family functioning been impacted by the child's diagnosis or specific needs?
- What is the extent of the family's support network for accessing emotional support and assistance with advocacy and other day-to-day needs such as respite?
- What resources has the family accessed or attempted to access? Which resources have been most helpful? What additional resources is the family interested in learning about or accessing?
- Are there financial needs related to basic family functioning or accessing services for the individual with an ASD?
- Does the family demonstrate a need for consultation regarding legal issues related to accessing services, financial planning, or guardianship?

### Instruments Used To Assess Family Functioning

- *Parenting Stress Index*
- Parent Interview
- Needs Assessment Tools Developed by Agencies or Clinicians

Few standardized instruments are available for assessing family functioning. The *Parenting Stress Index* may be used to identify which types of stressors are most problematic for a specific family and whether the level of reported parenting stress suggests a need for clinical intervention. Most often family functioning is assessed via direct interview and observation. The lack of standardized instruments requires the clinician to rely on clinical skill, judgment, and experience. Nonstandardized needs assessment tools may be developed by clinicians or agencies to more systematically assess family needs. Regardless of the instruments or procedures used, queries should be made in a supportive and non-judgmental manner with a clear explanation of why such information is relevant.

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# Appendices





## Summary of Best Practice Recommendations

SCREENING	PAGE
All professionals involved in the care of young children are aware of developmental indicators of ASDs.	21
All professionals responsible for the care of children perform routine developmental monitoring to identify children with atypical development.	23
Higher risk children receive more intensive monitoring and screening.	25
At a minimum, specific screening for ASDs occurs for all children at 18 and 24 months of age.	25
A positive screening results in an immediate referral for further evaluation of developmental concerns.	28
When indicators of ASDs are observed in the school setting, educational personnel discuss with parents the potential benefits of a diagnostic medical evaluation.	34
School and community professionals are adequately prepared to assure timely screening, referral, and diagnosis of persons with ASDs.	34
Community professionals elicit and respond to parents' concerns about their child's development and behaviors at every healthcare provider contact, including well- and ill-child visits.	35
Parents are included as full partners throughout the screening and referral process.	35
If developmental screening suggests an ASD, there is an immediate referral for further evaluation regardless of the age of the individual.	37
At-risk children and their parents are referred to intervention services and community supports based on their individual needs, even prior to completion of the ASD diagnostic evaluation.	40
Children at risk for ASDs and other developmental concerns are followed over time by primary care providers and other professionals in their community to ensure access to quality care.	40
Information about a child's development is communicated to parents with sensitivity and understanding, noting both strengths and concerns.	41
Effective communication with parents about their child's developmental progress is essential for early identification and intervention.	41

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DIAGNOSTIC EVALUATION	PAGE
The diagnosis of an ASD is made as soon as possible to facilitate intervention and initiate family support.	46
The lead diagnostic clinician is knowledgeable about typical child development; variability in presentation of ASD symptoms across age range, intellectual, and developmental levels; and non-autism spectrum disorders that can have symptoms similar to ASDs.	46
The lead diagnostic clinician is familiar with the psychometric properties and utility of ASD diagnostic instruments.	47
The lead diagnostic clinician is aware of the limits of his or her own clinical competence and utilizes standardized instruments, consultations, or referrals as necessary for accurate diagnostic decision making.	47
The lead diagnostic clinician has the knowledge, experience, and clinical judgment to conduct comprehensive evaluations that include two core elements: the individual's history, and direct interaction and observation of the individual.	56
The lead diagnostic clinician allots adequate time and materials to complete a review of relevant records, a thorough parent interview, and direct interaction and behavioral observation of the individual.	56
Face-to-face behavioral observation and interaction are essential components of diagnostic evaluation.	56
Completion of standardized behavior ratings or other data collection procedures by professionals in multiple settings provides valuable information about the individual's functioning.	58
The lead diagnostic clinician builds a partnership with parents and caregivers throughout the diagnostic evaluation process. This partnership begins by respecting parents' expertise about their child and focusing on parents' questions and concerns.	59
The lead clinician is able to differentiate ASDs from other developmental or psychiatric disorders with overlapping symptoms.	71
A family-centered evaluation entails spending sufficient time with parents to provide detailed feedback and answer all questions.	75
Evaluation reports are written in a manner that is accessible and understandable to parents and other service providers who may be involved in providing therapeutic, educational, social, or habilitative services.	76
Parents are encouraged to share the written evaluation report with other professionals who are providing ASD-related services, as appropriate.	76

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## APPENDIX A

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ASSESSMENT FOR INTERVENTION PLANNING	PAGE
Assessment for intervention planning requires collaboration with family members to prioritize domains of functioning to be addressed based on family concerns, functioning, and access to resources, as well as clinical indicators, intervention history, and prior assessments results.	81
Professionals involved in assessment for intervention planning understand the basic similarities and distinctions among the various service systems, including medical, educational, and other providers with whom individuals with ASDs and their families may be involved.	82
Assessment requires careful examination of individual functioning across multiple domains to direct intervention planning based on the individual's unique profile of strengths and concerns.	83
After initial assessment for intervention planning has been completed, the lead clinician remains available to the family to support coordination of care.	84
Community collaboration is enhanced when results of clinical, educational, and other community-based assessments are available for consideration across settings and service providers.	84
Professionals involved in assessment for intervention planning understand the role of assessment in development of an initial intervention plan and the need for continuous and ongoing assessment.	85
Assessment for intervention planning requires involvement of professionals representing multiple disciplines.	86
Professionals involved in clinical assessment for intervention planning have expertise in their fields and specific training and experience with ASDs. Professionals openly discuss their credentials and experience with ASDs with individuals involved in the assessment process including parents or other family members.	86
Individuals with ASDs, their families, and/or advocates are encouraged to inquire about the training and experience of professionals when selecting service providers.	86
Professionals involved in assessment for intervention planning consider available data from all prior assessments, including assessments conducted in clinical, educational, or other service settings.	87
Although each essential component is explored for all individuals diagnosed with ASDs, assessment for intervention planning is tailored to the unique needs of each individual and his or her family.	87
Assessment of cognitive and academic functioning is completed for all individuals diagnosed with ASDs.	88
Assessment of adaptive functioning is completed for all individuals diagnosed with ASDs.	89
For older children, adolescents, and young adults, assessment of adaptive functioning includes attention to skills and competencies required for transitions, such as transition from elementary to middle school or from home to residential living.	89

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ASSESSMENT FOR INTERVENTION PLANNING	PAGE
Assessment of social, emotional, and behavioral functioning includes consideration of possible coexisting social-emotional difficulties that might impact intervention planning.	90
Comprehensive assessment of social, emotional, and behavioral functioning is completed for all individuals diagnosed with ASDs.	90
Comprehensive assessment of communication skills is completed for all individuals diagnosed with ASDs.	90
All individuals diagnosed with ASDs require a comprehensive medical examination to assist in determining the presence of any associated medical conditions or health risk factors and to consider the underlying etiology of their neurobiological disorders.	91
Assessment of sensory and motor functioning is completed for all individuals diagnosed with ASDs to facilitate intervention planning.	92
Assessment of the family environment provides a context in which all essential components of assessment for intervention planning are considered.	92
The lead clinician and any other professionals completing assessments clarify their current and future roles in the individual's care.	93
Professionals talk explicitly with families about their concerns and the potential benefits of sharing relevant information with all service providers involved with the individuals with ASDs. The need for parental or individual consent to share information is discussed, and the important role that families can play in facilitating communication among providers is emphasized.	93
Assessment reports are written in a manner that is accessible and understandable to parents and other service providers and contain practical recommendations for next steps.	94
Following thorough discussion with family members, information about the standardized instruments used and specific test scores obtained are provided as part of the written report, when possible.	94

# Missouri Autism Guidelines Initiative

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## CDC's *Learn the Signs. Act Early.* List of Developmental Indicators

### IT'S TIME TO CHANGE HOW WE VIEW A CHILD'S GROWTH.

As they grow, children are always learning new things. These are just some of the things you should be looking for as your child grows. Because every child develops at his or her own pace, your child may reach these milestones slightly before or after other children the same age. Use this as a guide, and if you have any concerns, talk with your child's doctor or nurse.

#### By the end of 7 months, many children are able to:

- turn head when name is called
- smile back at another person
- respond to sound with sounds
- enjoy social play (such as peek-a-boo)

#### By the end of 1 year (12 months), many children are able to:

- use simple gestures (waving "bye-bye")
- make sounds such as "ma" and "da"
- imitate actions in their play (clap when you clap)
- respond when told "no"

#### By the end of 1-1/2 years (18 months), many children are able to:

- do simple pretend play ("talk" on a toy phone)
- point to interesting objects
- look at object when you point at it and tell them to "look"\*
- use several single words unprompted

#### By the end of 2 years (24 months), many children are able to:

- use 2- to 4-word phrases
- follow simple instructions
- become more interested in other children
- point to object or picture when named

**By the end of 3 years (36 months), many children are able to:**

- show affection for playmates
- use 4- to 5-word sentences
- imitate adults and playmates (run when other children run)
- play make-believe with dolls, animals, and people (“feed” a teddy bear)

**By the end of 4 years (48 months), many children are able to:**

- use 5- to 6-word sentences
- follow 3-step commands (“Get dressed. Comb your hair, and wash your face.”)
- cooperate with other children

**Questions to ask your child’s doctor or nurse:**

- What can I do to keep track of my child’s development?
- What should I do if I’m worried about my child’s progress?
- Where can I go to get more information?
- Can you refer me to a specialist for more information?

From Shelov, S., & Hannemann, R. (2004). *Caring for your baby and young child: Birth to age 5*. New York, NY: Bantam Books.

\* Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J. Wheelwright, S., & Drew, A. (2000). A screening instrument for autism at 18 months of age: A 6-year follow-up study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 39, 694-702.

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Available from [www.cdc.gov/ncbddd/actearly/pdf/hcp\\_pdfs/InformationalCard.pdf](http://www.cdc.gov/ncbddd/actearly/pdf/hcp_pdfs/InformationalCard.pdf)

# General Developmental Screening Instruments

SCREENING INSTRUMENT	AGE RANGE	DESCRIPTION	DEVELOPMENTAL DOMAINS COVERED
<b>PEDS</b> <i>Parents' Evaluation of Developmental Status</i> <a href="http://www.pedstest.com/">http://www.pedstest.com/</a> (Glascoe, 2006)	0–95 months (7 years, 11 months)	Via 10 questions, parents report their concerns in each developmental domain - (the same for all ages, answered “yes,” “no,” “a little”)	Domains include expressive language and articulation, receptive language, gross motor, fine motor, self-help, social-emotional, behavior, and global-cognitive
<b>PEDS:DM</b> <i>PEDS: Developmental Milestones</i> Parental report about a child's skills and behavior <a href="http://www.pedstest.com/">http://www.pedstest.com/</a> (Glascoe & Robertshaw, 2006)	0–95 months (7 years, 11 months)	6–8 items or questions, depending on the age level. Parents indicate a child's level of developmental skill in each domain using one of 22 age-specific questionnaires	All domains covered: Expressive and receptive language, gross motor, fine motor, self-help, social-emotional, behavior, and (for older children) reading and math
<b>ASQ – 3</b> <i>Ages and Stages Questionnaire</i> <a href="http://agesandstages.com">http://agesandstages.com</a> (Squires & Bricker, 2009)	1–66 months	Parental report about a child's skills and behavior – 21 separate questionnaires (answered yes, sometimes, not yet) plus 7–8 unscored Overall questions. Parents indicate a child's developmental skills, using one of 19 age-specific questionnaires	Domains include communication, gross motor, fine motor, problem-solving, and personal-social skills
<b>ASQ – SE</b> <i>Ages &amp; Stages Questionnaire: Social-Emotional</i> <a href="http://agesandstages.com/">http://agesandstages.com/</a> (Squires, Bricker, & Twombly, 2002)	6–60 months	Parent completes (4th to 6th grade reading level) child-monitoring system for social-emotional behaviors	Personal–social including self-regulation, compliance, communication, adaptive functioning, autonomy, affect, and interaction with people

SENSITIVITY	SPECIFICITY	ADMIN. TIME	SCORING
74–79%	70–80%	2–10 minutes	<ul style="list-style-type: none"> <li>■ Low, moderate, or high risk for each developmental domain</li> <li>■ Provides algorithm to determine whether to refer, do additional screening, or reassure parents that development is normal</li> </ul>
By domain: 75–87% Across ages: 70–94%	By domain: 71–88% Across ages: 77–93%	3–5 minutes	<ul style="list-style-type: none"> <li>■ Pass/fail score for each developmental domain</li> <li>■ Provides a cutoff score for children below the 16th percentile in each developmental domain</li> <li>■ The Assessment version enables users to compute age-equivalent scores and percentage of delayed or advanced development</li> </ul>
70–90%, except at the four-month age level	76–91%	15–30 minutes; Offers online management	<ul style="list-style-type: none"> <li>■ Takes 1–5 minutes</li> <li>■ Single pass/fail score for each developmental domain</li> <li>■ Provides a cutoff score in each developmental domain (2 standard deviations below the mean)</li> <li>■ Refer the child when the score falls below the cutoff in any area of concern</li> </ul>
Reliability is 94%; validity is between 75% and 89%		10–15 minutes to complete; 1–3 minutes to score	<ul style="list-style-type: none"> <li>■ Parents/caregivers complete one of 8 color-coded questionnaires for use at 6, 12, 18, 24, 30, 36, 48, and 60 months</li> <li>■ Professional scores the questionnaire</li> </ul>

## M-CHAT: Modified Checklist for Autism in Toddlers

*Editor's Note: The M-CHAT has been reprinted here with permission. More information is available at [www.mchatscreen.com](http://www.mchatscreen.com) or [www.firstsigns.org](http://www.firstsigns.org).*

### Instructions for Use

The *M-CHAT* is validated for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorders (ASD). The *M-CHAT* can be administered and scored as part of a well-child check-up, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the *M-CHAT* was to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk for ASD will be diagnosed with ASD. To address this, we have developed a structured follow-up interview for use in conjunction with the *M-CHAT*; it is available at the two websites listed above. Users should be aware that even with the follow-up questions, a significant number of the children who fail the *M-CHAT* will not be diagnosed with an ASD; however, these children are at risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who fails the screening.

The *M-CHAT* can be scored in less than two minutes. Scoring instructions can be downloaded from [www.mchatscreen.com](http://www.mchatscreen.com) or [www.firstsigns.org](http://www.firstsigns.org). We also have developed a scoring template, which is available on these websites; when printed on an overhead transparency and laid over the completed *M-CHAT*, it facilitates scoring. Please note that minor differences in printers may cause your scoring template not to line up exactly with the printed *M-CHAT*.

Children who fail more than 3 items total or 2 critical items (particularly if these scores remain elevated after the follow-up interview) should be referred for diagnostic evaluation by a specialist trained to evaluate ASD in very young children. In addition, children for whom there are physician, parent, or other professional's concerns about ASD should be referred for evaluation, given that it is unlikely for any screening instrument to have 100% sensitivity.

## M-CHAT

Please fill out the following about how your child usually is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.?	YES	NO
2. Does your child take an interest in other children?	YES	NO
3. Does your child like climbing on things, such as up stairs?	YES	NO
4. Does your child enjoy playing peek-a-boo/hide-and-seek?	YES	NO
5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?	YES	NO
6. Does your child ever use his/her index finger to point, to ask for something?	YES	NO
7. Does your child ever use his/her index finger to point, to indicate interest in something?	YES	NO
8. Can your child play properly with small toys (e.g., cars or blocks) without just mouthing, fiddling, or dropping them?	YES	NO
9. Does your child ever bring objects over to you (parent) to show you something?	YES	NO
10. Does your child look you in the eye for more than a second or two?	YES	NO
11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)	YES	NO
12. Does your child smile in response to your face or your smile?	YES	NO
13. Does your child imitate you? (e.g., you make a face-will your child imitate it?)	YES	NO
14. Does your child respond to his/her name when you call?	YES	NO
15. If you point at a toy across the room, does your child look at it?	YES	NO
16. Does your child walk?	YES	NO
17. Does your child look at things you are looking at?	YES	NO
18. Does your child make unusual finger movements near his/her face?	YES	NO
19. Does your child try to attract your attention to his/her own activity?	YES	NO
20. Have you ever wondered if your child is deaf?	YES	NO
21. Does your child understand what people say?	YES	NO
22. Does your child sometimes stare at nothing or wander with no purpose?	YES	NO
23. Does your child look at your face to check your reaction when faced with something unfamiliar?	YES	NO

(CONTINUED)



## APPENDIX D2

(CONTINUED)

### CUESTIONARIO DEL DESARROLLO COMUNICATIVO Y SOCIAL EN LA INFANCIA (M-CHAT/ES)

Seleccione, rodeando con un círculo, la respuesta que le parece que refleja mejor cómo su hijo o hija actúa NORMALMENTE. Si el comportamiento no es el habitual (por ejemplo, usted solamente se lo ha visto hacer una o dos veces) conteste que el niño o niña NO lo hace. Por favor, conteste a todas las preguntas.

1. ¿Le gusta que le balanceen, o que el adulto le haga el “caballito” sentándole en sus rodillas, etc.?	SÍ	NO
2. ¿Muestra interés por otros niños o niñas?	SÍ	NO
3. ¿Le gusta subirse a sitios como, por ejemplo, sillones, escalones, juegos del parque...?	SÍ	NO
4. ¿Le gusta que el adulto juegue con él o ella al “cucú-tras” (taparse los ojos y luego descubrirlos; jugar a esconderse y aparecer de repente)	SÍ	NO
5. ¿Alguna vez hace juegos imaginativos, por ejemplo haciendo como si hablara por teléfono, como si estuviera dando de comer a una muñeca, como si estuviera conduciendo un coche o cosas así?	SÍ	NO
6. ¿Suele señalar con el dedo para pedir algo?	SÍ	NO
7. ¿Suele señalar con el dedo para indicar que algo le llama la atención?	SÍ	NO
8. ¿Puede jugar adecuadamente con piezas o juguetes pequeños (por ejemplo cochecitos, muñequitos o bloques de construcción) sin únicamente chuparlos, agitarlos o tirarlos?	SÍ	NO
9. ¿Suele traerle objetos para enseñárselos?	SÍ	NO
10. ¿Suele mirarle a los ojos durante unos segundos?	SÍ	NO
11. ¿Le parece demasiado sensible a ruidos poco intensos? (por ejemplo, reacciona tapándose los oídos, etc.)	SÍ	NO
12. ¿Sonríe al verle a usted o cuando usted le sonríe?	SÍ	NO
13. ¿Puede imitar o repetir gestos o acciones que usted hace? (por ejemplo, si usted hace una mueca él o ella también la hace)	SÍ	NO
14. ¿Responde cuando se le llama por su nombre?	SÍ	NO
15. Si usted señala con el dedo un juguete al otro lado de la habitación... ¿Dirige su hijo o hija la mirada hacia ese juguete?	SÍ	NO
16. ¿Ha aprendido ya a andar?	SÍ	NO
17. Si usted está mirando algo atentamente, ¿su hijo o hija se pone también a mirarlo?	SÍ	NO
18. ¿Hace su hijo o hija movimientos raros con los dedos, por ejemplo, acercándose los a los ojos?	SÍ	NO
19. ¿Intenta que usted preste atención a las actividades que él o ella está haciendo?	SÍ	NO
20. ¿Alguna vez ha pensado que su hijo o hija podría tener sordera?	SÍ	NO
21. ¿Entiende su hijo o hija lo que la gente dice?	SÍ	NO
22. ¿Se queda a veces mirando al vacío o va de un lado al otro sin propósito?	SÍ	NO
23. Si su hijo o hija tiene que enfrentarse a una situación desconocida, ¿le mira primero a usted a la cara para saber cómo reaccionar?	SÍ	NO

# Resources for Screening and Referral

## APPENDIX E

### TYPICAL SOCIAL DEVELOPMENT AND SCREENING FOR RED FLAGS

Centers for Disease Control and Prevention (CDC), <i>Learn the Signs. Act Early.</i> program	<a href="http://www.cdc.gov/ncbddd/autism/actearly">http://www.cdc.gov/ncbddd/autism/actearly</a>
First Signs' ASD Video Glossary, on-line tool to help parents and professionals learn about red flags for ASD	<a href="http://www.firstsigns.org">http://www.firstsigns.org</a>
Mid-Missouri Autism Rapid Response Initiative brochure, <i>Could My Child Have Autism?</i>	<a href="http://www.dmh.mo.gov/developmentaldisabilities/officeofautismservices.aspx">http://www.dmh.mo.gov/developmentaldisabilities/officeofautismservices.aspx</a> . Click on Publications link
Mid-Missouri Autism Rapid Response Initiative training modules, Understanding Autism (Free through University of Missouri Extension Program)	<a href="https://extweb.missouri.edu/courses/">https://extweb.missouri.edu/courses/</a>

### SCREENING RESOURCES FOR PROFESSIONALS

American Academy of Pediatrics, <i>Caring for Children with ASD: A Resource Toolkit for Clinicians</i>	<a href="http://www.aap.org/publiced/autismtoolkit.cfm">http://www.aap.org/publiced/autismtoolkit.cfm</a>
CDC, National Center on Birth Defects and Developmental Disabilities, Healthcare Providers homepage	<a href="http://www.cdc.gov/ncbddd/autism/hcp-screening.html">http://www.cdc.gov/ncbddd/autism/hcp-screening.html</a>
Developmental Screening Toolkit for Primary Care Providers	<a href="http://www.developmentalscreening.org/index.htm">http://www.developmentalscreening.org/index.htm</a>
CDC <i>Learn the Signs. Act Early.</i> Developmental Milestones handout materials	<a href="http://www.cdc.gov/ncbddd/actearly/downloads.html">http://www.cdc.gov/ncbddd/actearly/downloads.html</a>
CDC <i>Go Out and Play!</i> Online toolkit to help early childhood educators monitor development	<a href="http://www.cdc.gov/ncbddd/actearly/pdf/ccp_pdfs/GOP_kit.pdf">http://www.cdc.gov/ncbddd/actearly/pdf/ccp_pdfs/GOP_kit.pdf</a>
Autism Speaks video for teachers, <i>How to Talk to Parents About Autism</i>	<a href="http://youtube.com/watch?v=xaWUsXk4nD8">http://youtube.com/watch?v=xaWUsXk4nD8</a>
First Signs' <i>Concerns About a Child, Making Observations</i>	<a href="http://www.firstsigns.org/concerns/index.htm">http://www.firstsigns.org/concerns/index.htm</a>
<i>Modified Checklist for Autism in Toddlers (M-CHAT)</i> and M-CHAT Interview	<a href="http://www.firstsigns.org/screening/tools/index_tools.htm">http://www.firstsigns.org/screening/tools/index_tools.htm</a>

### ACCESSING DIAGNOSTIC SERVICES

Parents and caregivers can reference any of these directories to locate diagnostic centers, physicians, and other types of services:	
Hosted by Autism Speaks	<a href="http://www.autismspeaks.org">www.autismspeaks.org</a>
Hosted by Autism Alliance of Greater Kansas City	<a href="http://www.autismalliancekc.org">www.autismalliancekc.org</a>
Hosted by Missouri Families for Effective Autism Treatment (MO-FEAT Autism Resource Directory)	<a href="http://www.mo-feat.org">www.mo-feat.org</a>

(CONTINUED)

**APPENDIX E**  
(CONTINUED)

ACCESSING STATE AND LOCAL AUTISM SERVICES	
A guide tailored to Missouri's system of care, <i>Navigating Autism Services: A Community Guide for Missouri</i> , includes basic services and where to go for assistance:	<a href="http://www.dmh.mo.gov/developmentaldisabilities/officeofautismservices.aspx">http://www.dmh.mo.gov/developmentaldisabilities/officeofautismservices.aspx</a>
State departments for early intervention and health care services, pages 7-8	
State departments providing support services for children and youth ages 3-21 years, pages 8-12	
Local, county-based funding or services provided by Senate Bill 40 Boards, page 10	
PARENT EDUCATION AND SUPPORTS	
Autism Speaks, <i>First 100 Days</i> , created to assist families in getting critical information in the first 100 days after a diagnosis	<a href="http://www.autismspeaks.org/community/family_services/100_day_kit.php">http://www.autismspeaks.org/community/family_services/100_day_kit.php</a>
Support groups for parents, caregivers, and siblings including social skills groups	<a href="http://www.dmh.mo.gov">http://www.dmh.mo.gov</a> Type Autism Support Groups in the search field
Missouri Developmental Disability Resource Center	<a href="http://www.moddrc.org">www.moddrc.org</a>
MPACT Missouri's Parent Training and Information Center	<a href="http://www.ptimpact.org">www.ptimpact.org</a>
Sharing Our Strengths—Missouri's Parent-to-Parent Support Network	<a href="http://www.sharingourstrengths.com">www.sharingourstrengths.com</a>
Autism Society of America's on-line referral database	<a href="http://www.autismsource.org">http://www.autismsource.org</a>

# Diagnostic Instruments

INSTRUMENT	<i>Autism Diagnostic Observation Schedule (ADOS)</i>	<i>Autism Diagnostic Interview-Revised (ADI-R)</i>	<i>Childhood Autism Rating Scale (CARS)</i>
<b>ASD SYMPTOMS ASSESSED</b>	Verbal and nonverbal communication, social interaction, restricted and repetitive behaviors and interests	Social interaction, verbal and nonverbal communication, and restricted and repetitive behaviors and interests	DSM-IV-TR symptoms along with symptoms from other diagnostic systems
<b>AGE RANGE</b>	2 years <sup>a</sup> to adults	Individuals with mental age of 2 years through adulthood	2 years and older
<b>VERSIONS</b>	Structured behavioral observation involving a series of tasks; Four different administration modules depending on language (e.g., Module One is for pre-verbal or nonverbal individuals) and developmental level	Standardized parent interview; Lifetime version, current version, and version for children under 4 years of age	
<b>ADMINISTRATION TIME</b>	30–45 minutes	1 1/2 – 3 hours	Approximately 20–30 minutes <sup>b</sup>
<b>PRACTITIONER SCORING TIME</b>	10–30 minutes	20–30 minutes	5–10 minutes
<b>SCORING INTERPRETING</b>	Algorithm including cutoff scores in the areas of social interaction and communication along with a total score; Cutoffs for autism and broader ASD cutoff	Cutoff scores in the areas of communication, social interaction, behaviors and interests, and abnormality of development	Overall cutoff scores for non-autistic and mild, moderate, or severe autism
<b>SENSITIVITY<sup>c</sup></b>	95%	89–90%	94%
<b>SPECIFICITY<sup>c</sup></b>	88%	56–62%	85%
<b>WEBSITE/ AUTHORS</b>	<a href="http://www.wpspublish.com">www.wpspublish.com</a> Lord, Rutter, DiLavore, & Risi (1999)	<a href="http://www.wpspublish.com">www.wpspublish.com</a> Le Couteur, Lord, & Rutter (2003)	Schopler, Reichler, & Renner (2004)

Note. ADOS sensitivity and specificity from a presentation by Akshoomoff, Corsello, and Stahmer (2009) at the International Society for Autism Research Conference (based on *N* of 123); ADI-R sensitivity and specificity from 2005 IMFAR poster by Corsello, Lord, Hus, and Qui (N of 490); CARS sensitivity and specificity from Perry, Condillac, Freeman, Dunn-Geier, and Belair (2005) (N of 274).

<sup>a</sup>Toddler Module in development. <sup>b</sup>Administration time varies based on whether ratings are based on observation of the child, parent interview, or review of records or a combination of these. <sup>c</sup>Sensitivity and Specificity are reported to reflect the range of data available regarding each instrument. Percentages provided reflect sensitivity and specificity for a diagnosis of Autistic Disorder. For all instruments in the table, sensitivity and specificity tend to be much lower for clinical diagnoses of Asperger's Disorder or PDD-NOS.

# Instruments for Assessment for Intervention Planning

	INSTRUMENT	AGE RANGE	DESCRIPTION
<b>ESSENTIAL COMPONENT</b>			
<b>Cognitive/Developmental</b>	1. <i>Wechsler Intelligence Scale for Children-Fourth Edition</i> (Wechsler, 2003)	6 to 16 years	Nationally normed standardized test of cognitive ability
	2. <i>Wechsler Preschool and Primary Scale of Intelligence-Third Edition</i> (Wechsler, 2002)	2 years 6 months to 7 years 3 months (number of subtests varies with age)	Nationally normed standardized test of cognitive ability
	3. <i>Stanford-Binet Intelligence Scales-Fifth Edition</i> (Roid, 2003)	2 to 89 years	Nationally normed standardized measure of intellectual ability
	4. <i>Differential Abilities Scale-Second Edition</i> (Elliott, 2007)	2 year 6 months to 7 years 11 months	Nationally normed standardized measure of intellectual ability
	5. <i>Leiter International Performance Scale-Revised</i> (Roid & Miller, 1997)	2 to 20 years	Nationally normed standardized nonverbal measure of intellectual ability
	6. <i>Comprehensive Test of Nonverbal Intelligence</i> (Hammill, Pearson, & Weiderholt, 1997)	6 to 89 years	Nationally normed standardized nonverbal measure of intellectual ability
	7. <i>Kaufman Assessment Battery for Children-Second Edition</i> (Kaufman & Kaufman, 2004)	3 to 18 years	Nationally normed, standardized test of cognitive ability
	8. <i>Wechsler Adult Intelligence Scale, Fourth Edition</i> (Wechsler, 2008)	16 to 90 years	Nationally normed standardized test of cognitive ability.
	9. <i>Bayley Scales of Infant and Toddler Development, Third Edition</i> (Bayley, 2005)	1 to 42 months	Nationally normed measure of development
	10. <i>Mullen Scales of Early Learning</i> (Mullen, 1995)	Birth to 68 months	Nationally normed measure of development

DOMAINS ASSESSED/TYPES OF SCORES PROVIDED	ADMINISTRATION TIME	SPECIAL CONSIDERATIONS	PUBLISHER
Provides Full Scale IQ and four index scores (verbal comprehension, perceptual reasoning, working memory and processing speed)	65 to 80 minutes	Use of General Ability Index when there are concerns about the effects of attention-concentration, processing speed.	PsychCorp
Provides Full Scale IQ, Verbal IQ, Performance IQ, Processing Speed, and General Language Composite	30 to 60 min		PsychCorp
Provides Full Scale IQ, Verbal IQ, Nonverbal IQ, Working Memory	*	Has a two subtest abbreviated IQ screener. Norms include very high and very low functioning individuals.	Riverside
Nonverbal IQ, Nonverbal Fluid Reasoning	*	Special Nonverbal Composite useful for children with hearing concerns. More sensitive assessment of extremely high and extremely low performance.	Harcourt Assessment
Visualization and reasoning and Attention and Memory. Full IQ (6 subtests) and Brief IQ (4 subtests)	90 minutes with different subtests for different age groups	Nonverbal measure	Stoelting
Problem solving, reasoning, and abstract thinking	40 to 60 minutes	Nonverbal Measure	Pro Ed
Provides Mental Processing, Fluid-Crystallized, and Nonverbal Indices	30 to 70 minutes	Mental Processing Index recommended for suspected autism	AGS Publishers
Provides Full Scale IQ and four index scores (verbal comprehension, perceptual reasoning, working memory and processing speed)	60 to 100 minutes	Use of General Ability Index where there are concerns about the effects of working memory and processing speed	PsychCorp
Provides measures of motor (fine and gross), language (receptive and expressive), and cognitive development	30 to 90 minutes	Parent report measure of Social-Emotional Adaptive Behavior available for use in conjunction with other BSID-III measures	Pearson
Five scales: Gross Motor, Visual Reception, Fine Motor, Expressive Language, and Receptive Language	15 to 60 minutes		Pearson (CONTINUED)

\* data unavailable

## APPENDIX G

(CONTINUED)

	INSTRUMENT	AGE RANGE	DESCRIPTION
<b>ESSENTIAL COMPONENT</b>			
<b>Adaptive Behavior</b>	1. <i>Vineland-II Adaptive Behavior Scales</i> (Sparrow, Cicchetti, & Balla, 2005)	Birth to 90 years	Measure of adaptive behavior based on a national sample. Survey and interview options for parent/caregiver report as well as teacher rating form
	2. <i>Adaptive Behavior Assessment System-Second Edition</i> (Harrison & Oakland, 2003)	Birth to 89 years	Nationally normed questionnaire for parent/caregiver and teacher report
	3. <i>Scales of Independent Behavior-Revised</i> (Bruininks, Woodcock, Weatherman, & Hill (1996)	Birth to 80 years	Structured interview or checklist; Norms based on national sample
<b>Medical</b>	1. Physical Examination	All ages	Physician exam for signs of illness or health risk factors
	2. Dysmorphology Examination	All ages	Specialized physician inspection for variations in facial or body structure
	3. Neurological Examination	All ages	Specialized physician assessment of central and peripheral nervous system functioning
<b>Social, Emotional, and Behavioral</b>	1. <i>Behavior Assessment System for Children-Second Edition</i> (Reynolds & Kamphaus, 2004)	2 years to 21 years 11 months; Self-report form age 6 to 18 years	Nationally normed behavioral rating scales including teacher, parent, and self-report versions
	2. <i>Achenbach Child Behavior Checklist and Teacher Report Form</i> (Achenbach, 1991)		
	3. <i>Diagnostic Interview Schedule for Children, Version IV</i> (Shaffer et al., 2000)	6 to 17 years	Caregiver and youth scales for ages 9 to 17; Caregiver only for 6 to 8 years
	4. <i>Autism Comorbidity Interview-Present and Lifetime Versions</i>	6 to 18 years	Semi-structured interview



DOMAINS ASSESSED/TYPES OF SCORES PROVIDED	ADMINISTRATION TIME	SPECIAL CONSIDERATIONS	PUBLISHER
Adaptive Behavior Composite and indices for Communication, Daily Living, Socialization, and Motor Skills (for younger children) and an optional Maladaptive Behavior Index	20 to 60 minutes Teacher rating: 20 minutes		PsychCorp
General Adaptive Composite; Three Adaptive Domains (Conceptual, Practical, and Social) and 10 individual Skill Areas	15 to 20 minutes		Western Psychological Services
Fourteen areas of adaptive behavior and areas of problem behavior	45 to 60 min for Full Scale; 15 to 20 min for Short form or Early Development Form	Individual Plan Recommendation form for tracking progress	Riverside Publishing
Age-based measurement, observation and inspection for physical abnormalities	10 to 15 minutes	Identify evidence of associated illness or clues to underlying etiology of ASD	
Comparison of visible variations with known pre-natal and genetic conditions	15 minutes	Identify associated prenatal-onset conditions or clues to underlying etiology of ASD	
Age-based testing of mental status, cranial nerve, motor, sensory, reflex, co-ordination, and gait functioning	10 to 15 minutes	Identify associated neurological disorders or clues to underlying etiology	
Various areas including anxiety, aggression, attention, atypical behaviors, social skills as well as adaptive behaviors such as activities of daily living and adaptability	10 to 20 minutes		Psych Corp
Behaviors such as anxious and depressive symptoms, rule-breaking behavior, and social problems	10 to 20 minutes		ASEBA/ADM
Structured interview that covers 36 DSM-IV disorders including anxiety, mood, and behavior disorder			NIMH
Adaptation of the Schedule for Affective Disorders and Schizophrenia in School Age Children specifically for children with ASDs	Up to 2 hours		Leyfer et al. (2006)  (CONTINUED)

## APPENDIX G

(CONTINUED)

	INSTRUMENT	AGE RANGE	DESCRIPTION
<b>ESSENTIAL COMPONENT</b>			
<b>Communication</b>	1. <i>Clinical Evaluation of Language Fundamentals—Fourth Edition</i> (Semel, Wiig, & Secord, 2003)	5 to 21 years	Nationally normed language assessment
	2. <i>Clinical Evaluation of Language Fundamentals—Preschool</i> (Wiig, Secord, & Semel, 1992)	3 to 6 years	Nationally normed
	3. <i>Preschool Language Scale—Fourth Edition</i> (Zimmerman, Steiner, & Pond, 2002)	Birth to 6 years 11 months	National norms
	4. <i>Peabody Picture Vocabulary Test—Fourth Edition</i> (Dunn & Dunn, 2007)	2 years, 6 months to 90+ years	National norms
	5. <i>Expressive One-Word Picture Vocabulary Test</i> (Brownell, 2000)	2 to 18 years	National norms
	6. <i>Test of Auditory Comprehension of Language—Third Edition</i> (Carrow-Woolfold, 1999)	3 years to 9 years 11 months	Nationally normed measure of receptive language skills
	7. <i>Test of Problem Solving 3: Elementary</i> (Huisinigh, Bowers, & LoGiudice, 2005)	6 to 12 years	Nationally normed measure of skills involved in verbal reasoning and problem solving
	8. <i>Test of Problem Solving 2: Adolescent</i> (Bowers, Huisinigh, & LoGiudice 2007)	12 to 17 years	Nationally normed measure of skills involved in verbal reasoning and problem solving
	9. <i>MacArthur-Bates Communicative Development Inventories, Third Edition</i> (Fenson, Marchman, Thal, Dale, Reznick, & Bates (2007)	8 to 37 months	Nationally normed assessment of language and communication
	10. <i>Reynell Developmental Language Scales—Third Edition</i> (Reynell & Gruber, 1990)	1 through 6 years	Nationally normed measure

DOMAINS ASSESSED/TYPES OF SCORES PROVIDED	ADMINISTRATION TIME	SPECIAL CONSIDERATIONS	PUBLISHER
Standardized scores in the areas of Core Language, Receptive Language, Expressive Language, Language Structure, Language Content, Language Memory, and Working Memory	30 to 60 minutes	Pragmatics Profile and Observation Rating Scale provide assessment of classroom language performance and the effects on social interaction	PsychCorp
Expressive and receptive language, language content, and language structure			Pearson Assessment
Total Language, Auditory Comprehension, and Expressive Communication	20 to 45 minutes		Pearson
One word receptive vocabulary	10 to 15 minutes		Pearson
One word expressive vocabulary	15 to 20 minutes		Western Psychological Association
Receptive spoken vocabulary, grammar, and syntax	10 to 20 minutes		Pearson
Making inferences, Negative questions, Predicting, Sequencing, Problem solving, and Determining causes	35 minutes		Lingui Systems
Making Inferences, Determining Solutions, Problem Solving, Interpreting Perspectives, Transferring Insights	35 minutes		Lingui Systems
Words and Gestures; Words and Sentences	20 to 40 minutes		Brookes Publishing
Verbal Comprehension Scale and Expressive Language Scale	25 to 30 minutes		Western Psychological Services (CONTINUED)

## APPENDIX G

(CONTINUED)

	INSTRUMENT	AGE RANGE	DESCRIPTION
<b>ESSENTIAL COMPONENT</b>			
<b>Communication</b> (CONTINUED)	11. <i>Test of Early Language Development, Third Edition</i> (Hresko, Reid, & Hammill, 1999)	2 years to 7 years 11 months	Norm-referenced, standard scores, age equivalents
	12. <i>Test of Language Development-Primary, Fourth Edition</i> (Newcomer & Hammill, 2008)	4 years to 8 years 11 months	Nationally normed measure
<b>Academic/Pre-Academic</b>	1. <i>Bracken Basic Concept Scale-Third Edition: Receptive</i> (Bracken, 2006)	3 years to 6 years 11 months	Nationally normed measure of school readiness
	2. <i>Wide Range Achievement Test-Third Edition</i> (Stone, Jastak, & Wilkinson, 1995)	5 to 75 years	Nationally normed measure of academic achievement
	3. <i>Wechsler Individual Achievement Test-Second Edition</i> (Wechsler, 2001)	4 to 85 years	Nationally normed measure of academic achievement
	4. <i>Woodcock-Johnson Tests of Achievement</i> (Woodcock, McGrew, & Mather, 2001)	2 to 90 years	Nationally normed measure of academic achievement
<b>Sensory and Motor</b>	1. <i>Sensory Profile</i> (Dunn, 1999)	3 to 10 years Adolescent and Adult Sensory Profile— 11 years+ Infant/Toddler Sensory Profile—birth to 36 months	Parent/caregiver and school versions with items rated on a 5-point Likert scale (short and long versions available)
	2. <i>Peabody Developmental Motor Scales, Second Edition</i> (Folio & Fewell, 2000)	Birth through 5 years	Norm referenced measure of motor skills

DOMAINS ASSESSED/TYPES OF SCORES PROVIDED	ADMINISTRATION TIME	SPECIAL CONSIDERATIONS	PUBLISHER
Receptive and expressive language	15 to 45 minutes		Super Duper Inc
Picture, relational and oral vocabulary; Syntactic understanding; sentence imitation; morphological completion, phonemic analysis, word articulation	1 hour		Psych Corp
Includes early communication skills and receptive labeling of shapes, sizes, colors, letters, numbers, and comparisons	Full test: 30 to 40 min, School Readiness Composite: 10 to 15 minutes	The Bracken Concept Scale Expressive can be used to compare comprehension to verbal labeling of concepts	Pearson
Standard scores and grade equivalent scores in the areas of Reading, Spelling, and Arithmetic	15 to 30 minutes	3 alternate forms to allow for testing at a later date	PAR, Inc
Standard scores and grade equivalent scores in the areas of Word Reading, Spelling, and Numerical Reasoning (abbreviated version) as well as several other areas of academic functioning (longer version) such as Written Expression	90 to 120 minutes (full version)	Short form (assesses three areas) and full form which assesses more comprehensively	Pearson
Designed to assess areas consistent with areas of IDEA	Approximately 5 minutes per subtest		Riverside
Nine factors including responsiveness to sensory input, sensory seeking, emotional reactive, low endurance/ tone, oral sensory sensitivity, inattention/distractibility, poor registration, sensory sensitivity, sedentary, and fine motor/perceptual	Dependent upon version		Psych Corp
Total Motor Quotient as well as a Gross Motor Quotient (comprised of Reflexes, Stationary, Locomotion and Object Manipulation subtests), and a Fine Motor Quotient (comprised of the Grasping and Visual-Motor Integration subtests)	45 to 60 minutes		Therapro  (CONTINUED)

## APPENDIX G

(CONTINUED)

	INSTRUMENT	AGE RANGE	DESCRIPTION
<b>ESSENTIAL COMPONENT</b>			
<b>Sensory and Motor</b> (CONTINUED)	3. <i>Bruininks-Oseretsky Test of Motor Proficiency</i> (Bruininks & Bruininks, 2005)	4 through 21 years	Standardized measure of fine and gross motor skills
	4. <i>Beery-Buktenica Developmental Test of Visual Motor Integration, Fifth Edition</i> (Beery, Buktenica, & Beery, 2004)	2 years to 18 years	Paper and pencil administered measure of visual-motor deficits
<b>Alternative Tools When Standardized Testing Cannot Be Completed</b>	<i>Augmentative Communication Assessment Profile</i> (Goldman, 1994)	Ages 3 to 11	Uses observations of the child
	<i>Developmental Assessment for Individuals with Severe Disabilities, Second Edition</i> (Dykes & Erin, 1999)	Functional level of birth to 6 years 11 months	
	<i>Brigance Inventory of Early Development-II</i> (Brigance, 2004)	Birth to 7 years	Criterion referenced measure
	<i>Developmental Profile-3</i> (Alpern, 2007)	Birth to 12 years 11 months	Parent interview
	<i>Early Learning Accomplishment Profile</i> (Chapel Hill Training Project, 2001)	Birth to 36 months	Criterion referenced measure
<b>Family Functioning</b>	<i>Parenting Stress Index, Third Edition</i> (Abidin, 1995)	Parents of children ages 1 month to 12 years	Parent completed questionnaire to assess parenting stress validated in the U.S. and other countries

DOMAINS ASSESSED/TYPES OF SCORES PROVIDED	ADMINISTRATION TIME	SPECIAL CONSIDERATIONS	PUBLISHER
Eight subtests: fine motor precision, fine motor integration, manual dexterity, bilateral coordination, balance, running speed and agility, upper-limb coordination, strength	15 to 20 minutes		Pearson
Provides standard scores and age equivalents in the areas of visual perceptual ability, fine motor coordination, and visual-motor integration	VMI: untimed (approx 10 to 15 minutes) Visual Perception: 3 minutes; Motor Coordination: 5 minutes		PsychCorp
Identifies skills related to use of unaided systems including signing, point, and picture exchange	*	Designed for use with individuals with ASD	Speechmark
Identifies level of assistance (if any) required by individual in completion of various tasks and assesses language, sensory-motor, daily living, academics, and social-emotional domains	*		PRO-Ed
Physical Development, Language Development, Academic/Cognitive, Daily Living, Social and Emotional Development	30 to 60 minutes		Curriculum Associates
Overall score as well as assessing areas of Physical Development, Adaptive Behavior, Social-Emotional, Cognitive, and Communication	20 to 40 minutes		Western Psychological Services
Assesses multiple areas including: Gross Motor, Fine Motor, Cognitive, Language, Self-Help, and Social Emotional			Kaplan Learning Company
Yields Total Stress Score and scaled scores for Parent and Child Characteristics	20 to 30 minutes (120 items long form; 36 items short form)		PAR Inc

\* data unavailable



## Missouri: Focus on Autism

### ADVISORY BODY

#### Missouri Commission on Autism Spectrum Disorders

The creation of an autism-specific commission was the foremost recommendation of the Blue Ribbon Panel report. With passage of Senate Bill 768 in 2008 by the General Assembly, the “Missouri Commission on Autism Spectrum Disorders” was established. Recommendation number three of the Blue Ribbon Panel report called for the creation of the Office of Autism Services within the Division of Developmental Disabilities. Senate Bill 768 established that office as well.

The Commission on Autism Spectrum Disorders is charged with making recommendations for a comprehensive, statewide plan for an integrated system of training, treatment, and services for people who have autism. As a prelude to its planning process, the Commission has adopted a framework intended to serve as a touchstone for the Commission’s planning. Within the framework, the Commission members committed to (a) addressing areas of improvement in access and services for persons of all ages; and (b) addressing four areas of concentration that include individual and family supports, healthcare, education, and workforce development. The Commission also endorsed the Missouri Autism Guidelines Initiative regarding screening, diagnosis, and assessment for intervention. The list of Commission members can be viewed at <http://governor.mo.gov/boards/show/AUTISM>.

### TASK FORCES AND RECOMMENDATIONS

#### Blue Ribbon Panel on Autism

April 2007 heralded an announcement forming Missouri’s first Blue Ribbon Panel on Autism charged with defining the state of autism in Missouri. The 16-member panel was composed of parents, physicians, educators, and service providers. The panel traveled throughout Missouri hearing testimony from hundreds of family members, people with autism, physicians, and autism specialists. Subsequently, in December 2007, a report was published identifying issues and suggesting recommendations on behalf of children, youth, and adults with ASDs. The complete report and its 36 recommendations can be viewed at <http://www.senate.mo.gov/autism/autism2007.pdf>.

#### Missouri School Boards’ Association Task Force

In 2008, the Missouri School Boards’ Association convened a task force on autism to provide a broader perspective on recommendations regarding public education contained in the 2007 Blue Ribbon Report on Autism. One function of the 32-member Task Force was to examine the roles and responsibilities of public education in the context of comprehensive services to ensure positive outcomes for children with ASDs. The Autism Task Force developed a set of 10 recommendations to improve early intervention services; to build capacity and promote improved services within public schools and state agencies; and to improve coordination and collaboration of services among public agencies, private agencies, and organizations. The Task Force, in their final publication, *Recommendations for Policy and Practice in Missouri*, recognized and endorsed the Missouri Autism Guidelines Initiative as the means for addressing Recommendation 4.a: Develop written standards and guidelines for evidence-based practices related to screening, diagnosis, and assessment.

The full report is available on the Missouri School Boards’ Association website: <http://www.msbanet.org/news/article.aspx/3844>.

## STATE DEPARTMENTS AND PROGRAMS

### Department of Mental Health

#### DIVISION OF DEVELOPMENTAL DISABILITIES AND THE OFFICE OF AUTISM SERVICES

The Division of Developmental Disabilities is the mental health agency in Missouri that specifically lists “autism” as one of the qualifying diagnoses to consider when determining eligibility for services. The Division’s statutory role is to address prevention, to reduce stigma, and to provide services to people who have developmental disabilities, including people with ASDs. The Division is housed within the Missouri Department of Mental Health and offers a wide array of community-based services for people of all ages with developmental disabilities. The Division conducts eligibility and assessment for services through its 11 regional offices (see Appendix I and note that the St. Louis Regional Office has 2 primary locations to serve the City of St. Louis and adjacent counties). The role of the Office of Autism Services is to provide leadership in program development for children and adults who have ASD, including establishment of program standards and coordination of program capacity. The Office of Autism Services lends administrative support and technical assistance to the Missouri Commission on Autism Spectrum Disorders, with special attention to the development of the state plan for an integrated system of care. Other priority issues are outreach and education targeted for individuals, families, and service coordinators. The Office of Autism Services is housed within the Division of Developmental Disabilities. For more information, see <http://www.dmh.mo.gov/developmentaldisabilities/officeofautismservices.aspx>.

#### MID-MISSOURI AUTISM RAPID RESPONSE INITIATIVE

The Mid-Missouri Autism Rapid Response Initiative is a model program sponsored by the Department of Mental Health, Division of Developmental Disabilities, piloted in central Missouri for children ages birth to 5 years. Parents and public and private agencies work in partnership to develop a collaborative, community-based program focused on early diagnosis and intervention. The program aims to:

- decrease wait times for diagnosis and interventions,
- provide family members with education and supports during the diagnostic process and immediately afterwards, and
- increase the number of children who are routinely screened for autism spectrum disorders.

The group has developed a brochure entitled “Could My Child Have Autism?” for distribution among the initiative partners to help answer questions about autism and to provide contact information for the Regional Offices administered by the Division. Regional brochures are also available that list local level contact information. The brochure entitled “Could My Child Have Autism” can be downloaded at <http://www.dmh.mo.gov/developmentaldisabilities/officeofautismservices.aspx>.

To provide family members and service coordinators with regional access to education about autism, the initiative has developed curriculum for a training module, “Understanding Autism.” This module is offered at no cost by the University of Missouri Extension Program.

#### MISSOURI’S AUTISM PROJECTS

Nearly two decades ago, Missouri’s “Autism Projects” were established as a vital communication link between public policy makers and the needs of individuals and families living with ASDs in Missouri. Now codified into statute, the program offers supports and services designed to enable individuals with autism to live at home and remain integrated within their communities. There are five regional parent advisory

## APPENDIX H

(CONTINUED)

councils and a state-level council charged with making recommendations to Missouri's Division of Developmental Disabilities on matters such as autism-related policy, funding models, and service providers. For the statutory reference, see <http://www.moga.mo.gov/statutes/c600-699/6330000220.htm>.

### Department of Elementary and Secondary Education

#### FIRST STEPS

The Department of Elementary and Secondary Education is Missouri's lead agency for the state's early intervention program entitled "First Steps." This program is designed for children, birth to age 3 years, who have delayed development or diagnosed conditions associated with developmental disabilities including children diagnosed with ASDs. First Steps offers coordinated services and assistance to very young children and their families. Types of services available include speech therapy, occupational therapy, physical therapy, service coordination, transportation, and applied behavior analysis. For a map of entry points and contact information see [www.dese.mo.gov/divspeced/FirstSteps/](http://www.dese.mo.gov/divspeced/FirstSteps/).

#### PROJECT ACCESS

Project ACCESS of Missouri State University is funded by the Missouri Department of Elementary and Secondary Education. This program provides autism resource information to public schools in the form of on-site and telephone consultations, as well as support via the Internet. In addition, Project ACCESS designs autism-specific professional development opportunities and trains professionally credentialed individuals to present these courses through regional staff development centers. These trainings are offered to Missouri school district staff and educators who work with youngsters ages birth to 21 years who have developmental disabilities including ASDs. More information is available at <http://education.missouristate.edu/access/>.

## Regional Office Points of Entry Division of Developmental Disabilities

Regional offices serve as the point of entry for services and supports through the Division of Developmental Disabilities within Missouri's Department of Mental Health. The Division's statutory role is to address prevention, reduce stigma, and provide services to persons who have developmental disabilities. The Division focuses on improving the lives of persons who have developmental disabilities by offering integrated, inclusive, and self-directed community-based supports with ongoing quality enhancement. More information is available at <http://www.dmh.mo.gov>. Click on Developmental Disabilities and type Regional Offices in the search field.

REGIONAL OFFICE	COUNTIES
Albany Regional Office (800) 560-8774	Andrew, Atchison, Buchanan, Caldwell, Clinton, Daviess, DeKalb, Gentry, Harrison, Holt, Nodaway, Worth
Central Missouri Regional Office (888) 671-1041	Benton, Boone, Callaway, Carroll, Chariton, Cole, Cooper, Howard, Moniteau, Morgan, Pettis, Randolph, Saline
Hannibal Regional Office (800) 811-1128	Audrain, Lincoln, Marion, Monroe, Montgomery, Pike, Ralls, Warren
Joplin Regional Office (888) 549-6634	Barry, Barton, Cedar, Dade, Henry, Jasper, Lawrence, McDonald, Newton, St. Clair, Vernon
Kansas City Regional Office (800) 454-2331	Bates, Cass, Clay, Jackson, Johnson, Lafayette, Platte, Ray
Kirkville Regional Office (800) 621-6082	Adair, Clark, Grundy, Knox, Lewis, Linn, Livingston, Macon, Mercer, Putnam, Schuyler, Scotland, Shelby, Sullivan
Poplar Bluff Regional Office (800) 497-4214	Butler, Carter, Dunklin, Howell, Oregon, Reynolds, Ripley, Shannon, Stoddard, Wayne
Rolla Regional Office (800) 828-7604	Camden, Crawford, Dent, Franklin, Gasconade, Iron, Maries, Miller, Osage, Phelps, Pulaski, St. Francois, Texas, Washington
Sikeston Regional Office (800) 497-4647	Bollinger, Cape Girardeau, Madison, Mississippi, New Madrid, Pemiscot, Perry, Ste. Genevieve, Scott
Springfield Regional Office (888) 549-6635	Christian, Dallas, Douglas, Greene, Hickory, Laclede, Ozark, Polk, Stone, Taney, Webster, Wright
St. Louis County Regional Office (800) 374-6458	St. Louis
St. Louis Regional Tri-County Office (800) 358-7665	St. Louis City, St. Charles, Jefferson

## Coordinated Early Intervening Services (CEIS)

In a medical context, ASD screening refers to the use of specific standardized instruments to identify an individual's risk for an ASD. In accordance with the Missouri State Plan for Special Education (DESE, 2007), screening has a different meaning for public schools. Screening refers to administering a standardized tool to a broad population of students to check for at-risk indicators, such as conducting a vision screening for all first graders. School staff is not permitted to individually observe or test a child when a disability is suspected outside of the evaluation process. Before using an autism screening instrument such as the *M-CHAT* with an individual child, public school staff would have to initiate formal evaluation procedures, including securing written parental consent. An exception would include using some screening or informal diagnostic instruments to inform instructional strategies for curriculum implementation as a function of intervention processes such as Alternative Intervention Strategies (AIS) or Coordinated Early Intervening Services (CEIS).

When a child has been referred for an eligibility determination under IDEA, school staff gathers information from multiple sources, such as behavioral observations and anecdotal records of teachers; daily work and end of unit or routine standardized assessments; health records; and other reports supplied by the parents, such as reports from outside service providers. The parents are invited to a meeting with school staff, including the child's teacher, to carefully review all of the information and determine if an evaluation is warranted. At the meeting, parents are asked to contribute information. If the team decides an evaluation to determine eligibility for special education services is warranted, an evaluation plan is drawn up. As part of the plan, the parents will be asked to share any medical reports that are relevant. They can give the school team copies of the reports or sign a release of records form permitting the medical source to provide the school with copies of report(s).

If the child is experiencing difficulty functioning in the school environment or accessing or progressing in the general curriculum, the school may initiate a formal process involving a student assistance team or provide the evolving best practice of Coordinated Early Intervening Services (CEIS). CEIS refers to intervening with specific teaching/learning strategies and or environmental supports at the first sign of a student struggling or falling behind same-aged peers. This process is a function of regular education and can include standardized screening measures to direct interventions. The process involves the parent(s) in discussion and decision making from the onset and occurs prior to consideration of a referral for special education eligibility. If a referral is later warranted, data on the effectiveness of various intervention strategies are considered as a component of eligibility determination.